Llywodraeth Cymru
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Substance Misuse Treatment Framework: Prevention, Diagnosis, Treatment and Support for Alcohol-Related Brain Damage

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1. Executive Summary

1.1 Summary findings

1.1.1 In tackling the problem of Alcohol-Related Brain Damage (ARBD) and working through the maze of all syndromes with wider diagnostic, treatment, legal, commissioning and funding issues, evidence from specialist ARBD services have begun to highlight that with clinically validated assessment tools, early identification of ARBD, with pharmacological, psychosocial interventions and having a rehabilitative model, ARBD – contrary to the popular myth – is a non-progressive condition.

1.1.2 Under-diagnosis of ARBD is an acknowledged issue not only within clinical settings, but also in the community. Failure to present at services, for reasons including stigma, is common. Patients may usually first become visible to services when they are assessed at home or in general hospital settings and rarely through direct referral to psychiatric services, where their needs might be more quickly identified.

1.1.3 High quality awareness, education and training around ARBD among health and social care staff is required to combat lack of knowledge and inimical attitudes, and to improve early identification, diagnosis and service quality.

1.1.4 In hospital and secondary care settings, patients with ARBD may present with cognitive damage due to a host of syndromes and it becomes important to differentiate these conditions with an emphasis on prevention of the more severe ARBD syndromes such as Wernicke-Korsakoff's syndrome. Therefore, safely managing an acute alcohol withdrawal as per National Institute for Health and Care Excellence (NICE) guidelines, use of Pabrinex® both for treating a suspected Wernicke-Korsakoff's syndrome and as a prophylactic treatment for high-risk individuals becomes imperative.

1.1.5 Neuropsychological testing offers an effective and relatively inexpensive method of ARBD diagnosis and provides a wealth of information regarding each person's symptomology in a frequently varied condition. However, neuropsychological test outcomes alone provide insufficient evidence for making ARBD diagnoses due to the multiple possible causes of impaired performance on such tests (e.g., head injuries, neurodegenerative diseases, poor pre-morbid functioning etc.). As a result, all neuropsychological test outcomes need to be considered in conjunction with a clinical diagnostic process and any additional assessment outcomes available in order to make accurate diagnoses.

1.1.6 Few dedicated services currently exist across the UK for the management of ARBD and, as a result, patients may be placed within a range of different service types such as adult mental health services, memory services and alcohol treatment services. Alcohol services may meet some of their needs but struggle to engage those with cognitive impairment. Older adult mental health services can provide longer term care for those with permanent cognitive impairment but many people with ARBD are younger than their threshold age (often 65) and these services generally do not have the expertise to deal with alcohol misuse (McCabe, 2006). As a result, patients can find themselves placed between services with disagreement over which service should take the lead.

1.2 Recommendations

Awareness raising, education and training

1.2.1 Development of a co-ordinated national awareness raising campaign for public, patients, families and carers – multi-media (radio, social media, television and print) regarding the potential risks of alcohol use on brain /cognitive function and where to seek support and referral.

1.2.2 Development and evaluation of targeted and appropriate Patient Information Leaflets (PILs) to patients, families and carers to provide education on the risks of continued alcohol consumption.

1.2.3 Development of a three tier nationally accredited (AGORED, RCGP and RCPsych), HEIW education and training programme on alcohol, medically-managed alcohol withdrawal and ARBD:

a. Tier 1 – Basic training providing an overview of alcohol, physical and psychological harms and ARBD for professionals working with those with or at risk of, ARBD (including health and social care workers, housing support, community and social workers) as well as individuals at risk. Focus on prevention and early identification.

b. Tier 2 - More detailed and comprehensive training including symptoms, assessment, mental capacity, screening tools and protocols for those working directly with individuals at risk of, or diagnosed with ARBD (e.g. Primary care, addictions psychiatrists/ psychologists, substance misuse professionals and social workers).

c. Tier 3 - Specialist assessment including capacity, diagnosis and management of ARBD for clinical and non-clinical specialists including

pre-registration and postgraduate opportunities and for those providing Tiers 1 and 2 training.

Prevention, assertive outreach and early identification

1.2.4 In line with the NICE, the Royal College of Physicians and the British Association for Psychopharmacology recommendations, Thiamine, both parenteral Pabrinex® and oral Thiamine should be available and prescribed as clinically indicated.

1.2.5 All medically-managed alcohol withdrawals should be undertaken in line with NICE clinical guidance and as part of a planned care pathway, in conjunction with local addiction specialist services and recorded on the patient management system within the clinical alcohol services.

1.2.6 Cognitive screening of individuals with a history of significant alcohol use should be routinely undertaken by trained professionals (on at least a quarterly basis if alcohol consumption continues) in clinical and community-based settings to identify those with risk of ARBD. Primary care should consider alcohol in any assessment regarding memory and cognitive function including younger patients.

1.2.7 Health Boards in conjunction with Substance Misuse Area Planning Boards in Wales should commission specialist Alcohol Liaison Assertive Outreach Teams, for patients at risk of, or diagnosed with ARBD.

Clinical care pathway

1.2.8 Establishment of dedicated ARBD Services within each Health Board, with ARBD clinical specialists, clinical psychologists, occupational therapists, social services and general medicine and timely access to treatment and care.

1.2.9 Establishment of regional inpatient centres of excellence for ARBD to support appropriate diagnostic assessment, research and evaluation on clinical and service delivery models.

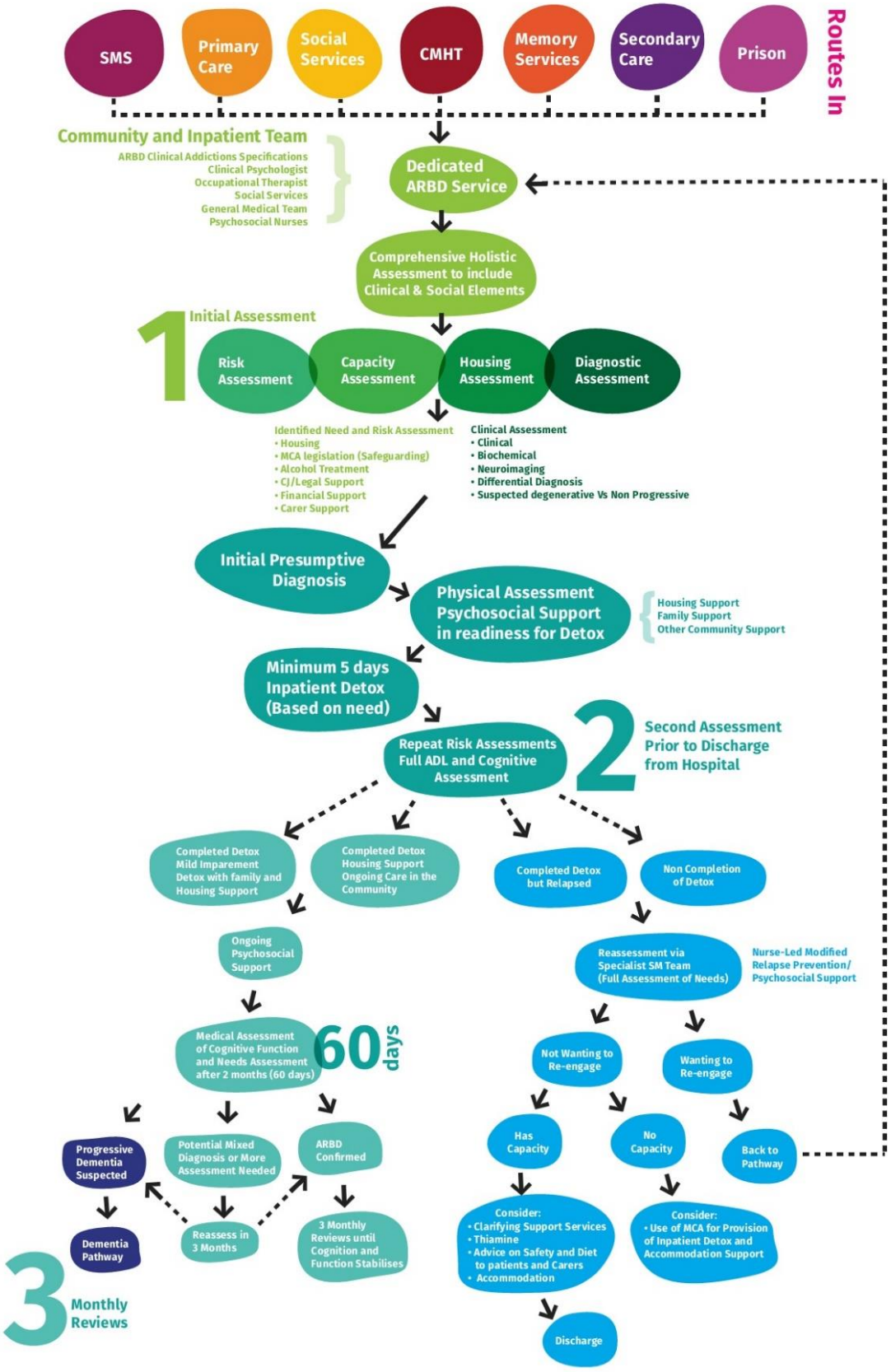
1.2.10 Social care, housing and allied services ensure comprehensive accommodation and care provision, tailored to assessed need and not requiring abstinence from alcohol as a prerequisite.

Maintaining and validating quality standard and service improvement

1.2.11 Support a comprehensive and co-ordinated programme of evaluation including validation of ARBD screening and diagnostic tools, rehabilitative models of care, integrated care pathways and community support services.

1.2.12 Support robust surveillance and clinical research studies to evidence the nature and scale of ARBD and at risk populations within Wales, identify pharmacological and dietary protective/risk measures and interventions and inform further planning and commissioning of integrated care.

Integrated Pathway for Alcohol Related Brain Damage



2. Background

2.1 Purpose and structure

2.1.1 This document is designed to inform and assist health and social care planners and providers to design and deliver quality, sustainable and equitable prevention and treatment services for those at risk of ARBD.

2.1.2 The intended audience includes service planners, commissioners, substance misuse and wider health and social care providers working with current or pre-existing problematic alcohol use.

2.1.3 The document provides an overview of the existing situation in Wales and the wider UK and outlines the evidence to inform improvements. Links to relevant strategy and policy documents are provided along with a summary of the evidence relating to required development of services aimed at improving the health and wellbeing of individuals with or at risk of developing ARBD.

2.1.4 This guidance document forms part of the suite of harm reduction and Substance Misuse Treatment Framework (SMTF) guidance for those working in Wales available at: Welsh Government Substance Misuse website

2.2 Strategic context

2.2.1 Following increased concern and publication of a number of key documents that have recently been published, including Alcohol Change UK's *'All in the Mind'*, Royal College of Psychiatrists (RCPsych) *'CR185 report'* and Public Health Wales (PHW*) 'Evidence – based profile of alcohol related brain damage in Wales'*

2.2.2 As a consequence of publications and highlighting the issue in Wales, the Welsh Government Substance Misuse Delivery Plan 2016-18 and latest Substance Misuse Delivery Plan 2019-22[1], outlined specific actions to raise awareness, improve training, education and diagnosis and establish clear pathways for referral and treatment (see Section 3).

2.3 Methodology

2.3.1 To oversee development of the SMTF for ARBD, a Project Board was established in 2015 and from the Project Board membership, the ARBD working group was developed to draft the SMTF to publication.

[1] Substance Misuse Delivery Plan-2019-2022

2.3.2 The evidence within this document is drawn from a range of sources including bibliographic databases, personal communication with leading ARBD academics, evidence gathering events and key informant interviews. The databases and website sources included MEDLINE, MEDLINE Daily Update, AMED, BNI and EMBASE. Websites included NICE, Health Protection Agency, Welsh Government and Department of Health.

2.4 Roles and responsibilities

2.4.1 Welsh Government, Health Boards, criminal justice, local authorities and third sector organisations will be responsible for ensuring delivery of the SMTF for ARBD. Multi-disciplinary ARBD working groups should develop an action plan focusing on areas for development within and across services.

2.5 Definition and key issues

2.5.1 ARBD is an umbrella term used to describe a spectrum of conditions characterised by chronic cognitive impairment due to changes in the structure and function of the brain attributed to excessive alcohol consumption over time (see Figure 1)**.**

2.5.2 One of the most well-known and severe types of ARBD is Wernicke-Korsakoff's Syndrome (WKS), a two phase disorder that proceeds from Wernicke's Encephalopathy (WE) on to Korsakoff's Syndrome (KS). WE is an acute neuropsychiatric condition that is characterised by confusion, cerebellar ataxia and oculomotor dysfunction (ophthalmalgia, nystagmus); though is also frequently associated with peripheral neuropathy, disorientation and the onset of a coma (Caine et al., 1997). The second phase, KS, is a prolonged disorder characterised by a profound memory deficit (anterograde amnesia) and milder impairments in executive function (including poor planning and decision-making capabilities), visuospatial processing and attention (Heirene, John, Roderique-Davies, 2018a).

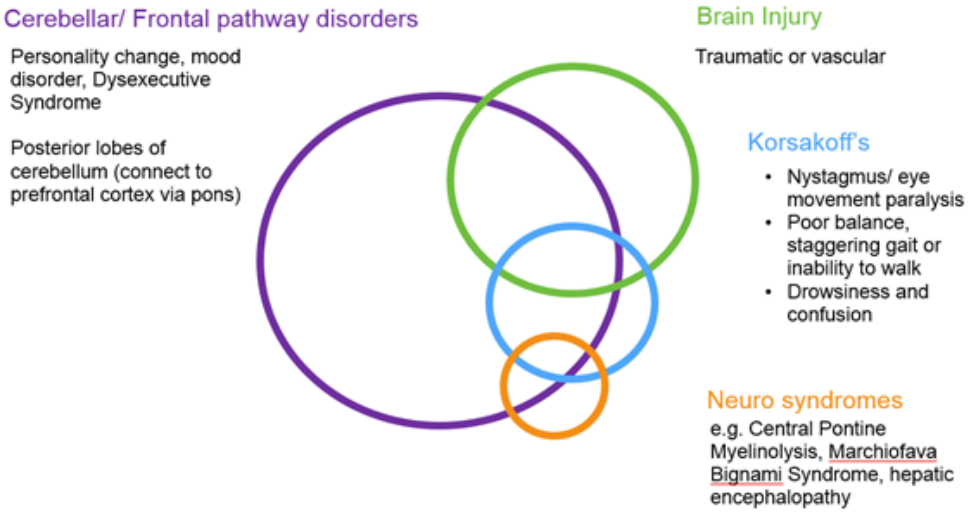


Figure 1 – ARBD, adapted from Wilson et al (2015)

2.5.3 WKS is believed to be caused by thiamine (vitamin B1) deficiency and, as a result, can occur in anyone prone to vitamin deficiencies (e.g., those with eating disorders). However, in contemporary Western societies, WKS is primarily seen in those with alcohol dependence due to their poor nutritional intake and the disruptive effects of alcohol on the absorption and metabolism of thiamine.

2.5.4 Despite including a diverse range of conditions, ARBD has proven a useful way to define a category of patients with common social and clinical needs and similar prospects for rehabilitation.

2.5.5 Evidence from specialist ARBD services has begun to highlight that, with clinically validated assessment tools, early identification of ARBD with pharmacological, psychosocial interventions and having a rehabilitative model:

- ARBD is a non-progressive condition provided abstinence is achieved.
- Acute hospital bed day usage can be reduced by up to 85%.
- Quality of life can be dramatically improved in individuals, with as high as 75% of them being cared and managed in non-institutional community settings (Wilson et al., 2012).

ARBD is not a degenerative condition if the patient stops drinking. It has been estimated that up to 75% can achieve some degree of recovery with appropriate rehabilitative support.

2.5.6 Under-diagnosis of ARBD is an acknowledged issue not only within clinical settings, but also in the community. Failure to present at services, for reasons

including stigma, is common. Patients usually first become visible to services when they are assessed at home or in general hospital settings and rarely through direct referral to psychiatric services, where their needs might be more quickly identified.

2.5.7 The progression of WE into KS may be halted if treated early with parental thiamine and appropriate management of withdrawal. Yet, approximately 56-85% of patients with WE go on to develop KS (Cook et al., 1998; Wood et al., 1986), significantly reducing the likelihood of their full recovery. Thus, early recognition and timely intervention is vital to improve prognoses.

2.5.8 In hospital and secondary care settings, patients with ARBD may present with cognitive damage due to a host of syndromes, as outlined in **Table 1** below, and it becomes important to differentiate these conditions with an emphasis on prevention of the more severe ARBD syndromes such as WKS. Therefore, safely managing an acute alcohol withdrawal as per NICE guidelines, use of Pabrinex® both for treating a suspected WKS and as a prophylactic for high risk individuals, becomes imperative.

Table 1. Alcohol-Related Brain Damage Syndromes

(David et al., 2009; Kopelman, 1991).

NEUROLOGICAL	NEUROPSYCHIATRIC
- Acute/Chronic Dysarthria and/or ataxia - Seizures- withdrawals, hypoglycaemia, trauma & precipitation of epilepsy - Peripheral Neuropathy - Degenerative Syndromes- corpus callosum, central pontine myelinolysis, cerebellar atrophy, optic neuritis etc.	Acute/Subacute - Acute withdrawals & Delirium Tremens - Alcoholic hallucinosis - Alcoholic Blackouts - Wernicke's Encephalopathy - Hepatic Encephalopathy - Pellagra Encephalopathy Chronic - Coarsening of personality- frontal lobe atrophy - Korsakoff's Syndrome - Cognitive deterioration- cortical atrophy

2.5.9 Multiple issues around presentation to clinical services and diagnosis can lead to cases being missed, undiagnosed or misdiagnosed including:

- The requirement for a period of abstinence prior to diagnosis.
- Lack of appropriate guidelines, education and training (or guidelines not put into practice) across services including psychiatric inpatient wards, GP practices and Emergency Departments.
- Overlap with non-alcohol related conditions such as other dementias.
- Variable or incomplete clinical signs.
- The broad spectrum of damage associated with ARBD.
- The possibility that standard brief cognitive assessment tools may miss less severe damage.
- Historical lack of specific diagnostic/assessment tools – or agreement of suite of assessment tools.
- Presence of co-morbidities.

3. Education, awareness raising, training and workforce development

3.1 Background

3.1.1 A report exploring the care of those with ARBD in North Wales found that those with the condition may have stopped drinking sooner had they known that the brain damage caused could be improved by abstinence (Boughy, 2007).

3.1.2 A lack of knowledge and understanding of ARBD among nursing and medical staff in the UK has been repeatedly highlighted as a barrier to improving the care and support of those with the condition (Boughy, 2007; Heirene et al., 2021; Wilson, 2011).

3.1.3 Poor knowledge of ARBD is problematic as the acute symptoms of WE are often confused with those of intoxication particularly within Emergency Departments (Sechi & Serra, 2007) or missed altogether (Harper, Giles, & Finlay-Jones, 1986), resulting in a failure to intervene at a time when the condition's prognosis could be greatly improved by intervention.

3.1.4 The lack of knowledge surrounding ARBD is further complicated by the stigmatisation and marginalisation of this group, which is likely to be even greater than that of individuals with substance misuse disorders without brain damage (Oudman et al., 2018; Schölin et al., 2019; Heirene et al., 2021).

3.1.5 Beliefs may exist around personal responsibility, for example, "… they brought the problem [alcoholism] on themselves" and that they do not "deserve" treatment (Svanberg, Morrison, & Cullen, 2015). However, the evidence does not support this view. Studies have demonstrated that those with alcohol use disorders frequently experience a variety of factors that place them at more risk of developing the disorder, including adverse childhood experiences (e.g., sexual abuse, neglect), family history of alcohol misuse, highly stressful and/or traumatic life events, and psychological disorders such as depression and anxiety (e.g., Pilowsky et al., 2009). Further, the harms associated with consumption are also moderated via several factors, including socioeconomic status and education level. For example, those from lower socioeconomic strata, compared to those from higher strata, have been found to be more likely to experience cognitive decline as a result of alcohol consumption (Sabia et al., 2011).

3.1.6 Those with ARBD may be perceived as "unmotivated" or "unwilling" to engage with services due to damage to the areas of their brain responsible for motivation and behaviour change (Beaunieux, et al, 2015; Heirene et al., 2021). This may in turn lead to what has been termed "therapeutic nihilism", in

which clinicians feel unable to effect meaningful change (Svanberg et al., 2015).

3.1.7 Other changes to the areas of the brain responsible for behavioural control can result in impulsive and/or aggressive behaviour (Beaunieux et al., 2015), again engendering negative perceptions of this group and increasing their marginalisation.

3.2 Evidence

Education and awareness raising in the public

3.2.1 Awareness raising in the general population is required to support the prevention and identification of at-risk individuals, to promote early engagement, diagnosis and treatment (RCP, 2014; Emmerson and Smith, 2015).

3.2.2 The RCP (2014) provide a brief patient and public information leaflet[2] providing an outline of what ARBD is, how it is caused and what treatment options are available. Similarly, Alcohol Change UK offer a range of 'fact-sheets' relating to ARBD, and these can be found on the charity's website.[3]

3.2.3 The wide-spread dissemination of information via leaflets and other forms of mass and multi-media such as radio and TV soap opera story line campaigns may increase public awareness and understanding of ARBD, potentially decreasing the stigma faced by this population and increasing early recognition.

3.2.4 Randomised clinical trials suggest that providing PILs in clinical settings can have a number of benefits, including increased patient knowledge and satisfaction and greater adherence to treatment, diet and lifestyle advice (Sustersic et al., 2017).

3.2.5 Research has highlighted a number of factors that can improve the effectiveness of PILs, including, for example, the inclusion of pictures or pictograms (Colledge et al., 2008). Sustersic and colleagues (2017) provide a checklist to ensure the quality of PILs is based on the best available evidence to date. This checklist includes items related to the content (e.g., based on the latest evidence-based medicine) and design (e.g., simple syntax and vocabulary) of PILs. The benefits of PILs may be augmented by using the "Teach back" method in which the patient is asked to "teach" it to their clinician

[2] Royal College of Psychiatrists Alcohol Related Brain Damage patient and public information leaflet 2014.
[3] Alcohol Concern Fact Sheet 'Alcohol Related Brain Damage – what is it?

after having read it at home or earlier in the session. Employing this method can identify those who may have poor health literacy and have struggled to assimilate the information provided (Colledge et al., 2008).

3.2.6 Colledge et al. (2008) have recommended that in addition to PILs, health information can be disseminated in a variety of other formats, including audio recordings, websites and videos. Evidence suggests these methods may be equally or more effective ways of delivering health-related information (Suggs, 2006), although fewer rigorous evaluations of their accuracy are available.

3.2.7 A 2010 review of mass media campaigns aimed at changing health behaviour suggested a number of factors can improve their effectiveness (Wakefield, Loken & Hornik, 2010):

- All campaign messages should result from sound research of the target group (e.g., alcohol users and their families) and be piloted with them.
- Behaviour is most likely to be influenced if campaign messages are delivered in areas where the requisite services are available to support people with the condition/behaviour.
- Sufficient funding must be available to ensure frequent and widespread exposure of campaign messages.

Education, awareness raising and training for patients, families and carers

3.2.8 To date, no research has investigated awareness raising strategies for ARBD, but the same strategies used for augmenting public awareness (e.g., PILs and public media campaigns) may be applicable to this group.

3.2.9 Alcohol Change UK offer a specific fact-sheet providing guidance on caring for someone with the condition for the families and carers of someone with ARBD.[4] They also provide three legal factsheets covering decision making, lasting power of attorney and the Mental Capacity Act, which may be particularly useful for those families and carers. Again, education and awareness in this population could also be achieved through the other more general leaflets and factsheets discussed above. [5]

3.2.10 Specific training courses for families and carers could also be of significant value. Alcohol Change UK state that they cover this area to some extent in their training programme,[6] although no specific courses are known to the authors.

[4] Alcohol Change UK 'Alcohol-Related Brain Damage - Road to Recovery: A handbook for the families, carers and friends of people with Alcohol Related Brain Damage.'

[5] Alcohol harms. Time for change. Factsheets | Alcohol Change UK

[6] Alcohol Change UK. Alcohol Related Brain Damage – Road to recovery handbook

Education, awareness raising and training for health and social care professionals

3.2.11 High quality awareness, education and training around ARBD among health and social care staff is required to combat lack of knowledge and inimical attitudes, and to improve early identification, diagnosis and service quality.

3.2.12 At present, there is a dearth of evidence outlining or evaluating training and education programmes on ARBD. The lack of available training has been highlighted as a significant barrier to improving ARBD service provision in Wales.

3.2.13 Introductory courses are currently available via Alcohol Change UK and NewLink Wales. The Royal College of General Practitioners (RCGP) also offer a certificate in Management of Alcohol and Primary Care now offer a one-day introductory course available across the UK.

3.2.14 Thomson et al. (2012) have suggested the NICE (2010a, b, 2011) guidance on alcohol-use disorders can be used to structure training and increase the identification of alcohol-related harms. These guidelines have, however, been criticised for a lack of specification regarding thiamine administration and dosing recommendations (Bell, 2012), highlighting the need to also consult up-to-date empirical evidence to inform ARBD training. In 2020 The Royal College of Psychiatrists endorsed an ARBD awareness raising training package developed by the University of South Wales.[7]

3.3 Recommendations

3.3.1 Development of a co-ordinated national awareness raising campaign for public, patients, families and carers – multi-media (radio, social media, television and print) regarding the potential risks of alcohol use on brain/cognitive function and where to seek support and referral.

3.3.2. Development and evaluation of targeted and appropriate Patient Information Leaflets (PILs) to patients, families and carers to provide education on the risks of continued alcohol consumption.

3.3.3 Development of a three tier nationally accredited (AGORED, RCGP and RCPsych), HEIW education and training programme on alcohol, medically-managed alcohol withdrawal and ARBD:

[7] Royal College of Psychiatrists. Alcohol-Related Brain Damage in Wales

i. Tier 1 – Basic training providing an overview of alcohol, physical and psychological harms and ARBD for professionals working with those with or at risk of, ARBD (including health and social care workers, housing support, community and social workers) as well as individuals at risk. Focus on prevention and early identification.

ii. Tier 2 - More detailed and comprehensive training including symptoms, assessment, mental capacity, screening tools and protocols for those working directly with individuals at risk of, or diagnosed with ARBD (e.g. Primary care, addictions psychiatrists/ psychologists, substance misuse professionals and social workers).

iii. Tier 3 - Specialist assessment including capacity, diagnosis and management of ARBD for clinical and non-clinical specialists including pre-registration and postgraduate opportunities and for those providing Tiers 1 and 2 training.

4. Prevention of Alcohol-Related Brain Damage amongst high risk populations

4.1 Background

4.1.1 It is becoming increasingly clear that there is an association between alcohol consumption and structural and functional abnormalities of the brain that are in turn associated with cognitive decline, and at levels of consumption within current recommended safe levels [Topiwala et al., 2017; Puimatti et al, 2018). However, cognitive deficits are most apparent in those who are chronic or dependant users of alcohol (e.g. Wernicke-Korsakoff Syndrome) (Sechi & Serra, 2007; Harper, 2009), brain weight is reduced in dependant alcohol users (Harper & Blumbergs, 1982) and the extent of atrophy is associated with lifetime consumption of alcohol measures (Harding et al, 1996).

4.1.2 One putative mechanism linking alcohol consumption with structural and functional abnormalities of the brain concerns the metabolism of thiamine hydrochloride. In those who use alcohol to excess, thiamine deficiency can emerge due to self-neglect, inadequate diet, the decreased transport of thiamine across intestinal mucosa, the low capacity of the liver to store the vitamin, and the impaired conversion of thiamine to the active compound thiamine pyrophosphate, a derivative of thiamine that is essential to the proper function of the nervous system (Sechi & Serra, 2007; Hoyumpa, 1980; Thomson, 2000).

4.1.3 Genetic and environmental factors may also contribute, as can magnesium deficiency (Sechi & Serra, 2007). If alcohol-related abnormalities are a consequence of alcohol disrupting the availability of thiamine, then such abnormalities can be prevented or treated through replenishing levels of thiamine. NICE, the Royal College of Physicians and the British Association for Psychopharmacology (NICE, 2010; NICE, 2011; Thomson et al, 2002; Lingford-Hughes et al, 2012) all recommend parenteral high dose thiamine as a prophylactic for those at risk of WKS.

4.1.4 According to guidelines (NICE, 2010; NICE, 2011; Thomson et al, 2002; Lingford-Hughes et al, 2012), patients undergoing acute alcohol withdrawal should be treated with benzodiazepine or carbamazepine. In people with delirium tremens, oral lorazepam may be offered as first-line treatment and parenteral lorazepam, haloperidol or olanzapine if symptoms persist. Oral or parenteral thiamine should be offered to those with suspected or are at elevated risk of developing WE. Dose is at the upper end of the British National Formulary range (see Appendix B).

4.2 Evidence

4.2.1 WE results from an acute deficiency of thiamine while KS is a chronic neurologic consequence of WE. There has been one Cochrane Review on the use of thiamine as a treatment for WKS (Day et al, 2013). The review covered all “randomized trials in which treatment with thiamine or thiamine-containing products was administered and compared with alternative interventions for people with, or at risk of developing, WKS secondary to alcohol abuse.” Two studies were identified, only one (Ambrose et al, 2001) of which was suitable for inclusion but contained methodological shortcomings.

4.2.2 A more general and recent review on treatments for ARBD and the subcategory WKS was published in 2013 (Ambrose et al, 2001). This review found tentative evidence to support guidance for rehabilitation, although highlighted weak methods in the available research literature and the review was further limited by a small number of relevant studies. None of the studies included in the review considered high-dose IV thiamine as an intervention, being mostly cross-sectional (e.g. patients with KS vs. controls) and focused mostly on forms of cognitive rehabilitation. Outcomes were mostly concerned with aspects of memory access and related executive function.

4.2.3 Whilst one extreme of ARBD is the classical presentation of WKS, the other milder or the less obvious form more frequently seen in clinical settings is the frontal lobe dysfunction. The majority of these people present with cognitive damage as a result of the direct toxic effects of alcohol and vitamin deficiencies from secondary neuropsychiatric conditions. WKS is a reversible and treatable condition in its early stages of onset. It therefore follows that one of the simplest and most obvious methods of preventing ARBD is reducing the total alcohol consumption in the population and supplementing Vitamin B1 at a local and population level.

4.2.4 In addition to the concerns surrounding thiamine depletion, a number of studies have identified associations between depletions of other vitamins and minerals and alcohol-related neurological complications. For example, low levels of zinc have been associated with an increased likelihood of experiencing delirium tremens and prolonged hallucinations during withdrawal (Bogden & Troiano, 1978), and deficiencies in other B vitamins such as niacin (B3) and pyridoxine (B6) are known to underpin various neurological disorders associated with alcohol misuse (i.e., Pellagra and alcoholic seizures, respectively; Cook, Hallwood, & Thomson, 1998). Moreover, subclinical deficiencies of vitamins A, C, D and E have all been observed and tentatively implicated as contributors to the neurocognitive impairment experienced by alcohol dependent individuals (Bogden & Troiano, 1978; Cook et al., 1991). Finally, a consideration of magnesium levels in those with or suspected of

ARBD may be particularly important due to the vitamin's crucial role in the conversion of thiamine to its neurologically useable state: thiamine pyrophosphate (Sechi & Serra, 2007). Thus, a severe magnesium deficiency may result in refractory WKS if left untreated (Traviesa, 1974). When completing blood test for alcohol use disorder patient, including magnesium routinely under urea and electrolyte (U&Es) blood test requests is required. Depending on levels, supplement magnesium should be provided.

4.3 Recommendations

4.3.1 In line with NICE, the Royal College of Physicians and the British Association for Psychopharmacology recommendations, Thiamine, both parenteral Pabrinex® and oral Thiamine should be available and prescribed as clinically indicated.

4.3.2. Support robust surveillance and clinical research studies to evidence the nature and scale of ARBD and at risk populations within Wales, identify pharmacological and dietary protective/risk measures and interventions and inform further planning and commissioning of integrated care.

5. Early identification

5.1 Background

5.1.1 The early identification and diagnosis of ARBD can significantly improve subsequent treatment outcomes. The symptoms of WE, for example, can be largely relieved via treatment with parenteral thiamine if recognised early (Day et al., 2013).

5.1.2 The historical under-diagnosis of ARBD (see also: Harper, 1983; Harper, Giles, & Finlay-Jones, 1986) has been attributed to the lack of training, stigma surrounding those with substance abuse problems, and the challenge of differentiating between the similar presentations of WE and intoxication (Sechi & Serra, 2007; Thomson, Guerrini, Bell, et al., 2012).

5.1.3 Early identification is further complicated by the heterogenous presentation of ARBD (Bowden, 1990) and the frequent comorbidities (e.g., depression, unspecified encephalopathy etc.) that accompany the condition (Wilson et al., 2012).

5.1.4 Due to the nature of the cognitive impairment in ARBD and lack of awareness of the condition among some clinical staff, many patients are not picked up by clinical services until they experience significant cognitive impairment (ARBIAS, 2009). Memory loss is easily recognised by family and friends but frontal lobe dysfunction, which is frequently the initial feature of ARBD, may not be recognised as the characteristic dysexecutive syndrome and may be incorrectly labelled as a lack of motivation and disorganisation secondary to intoxication (Cummings, 2005; Schmidt et al., 2005).

5.1.5 Despite the challenges currently facing the early identification of ARBD, a number of methods are available for screening and diagnostic purposes. Neuropsychological (or cognitive) assessment has been proposed as the most reliable method of diagnosing ARBD (Hayes, Demirkol, Ridley, Withall, & Draper, 2016), with a focus on tests of memory and executive functioning. However, several other modes of assessment can also provide clinically valuable information about a person's condition and should also be considered. These include neuroimaging investigations, nutritional status evaluations and assessments of activities of daily living (Horton, Duffy, Hollins Martin, & Martin, 2015) – see Chapter 6.

5.2 Evidence

Early signs and symptoms

5.2.1 Given the severity of WE and its poor prognosis if left untreated (historically a 20% fatality rate; Harper et al., 1986), familiarity with the early signs of thiamine deficiency can play an important role in early identification. Accordingly, the clinical indicators of early and late-stage thiamine deficiency outlined by Thomson, Guerrini, and Marshall (2012) are presented below (see Appendix A for other ARBD diagnostic criteria as preliminary guides for identification and diagnosis).

Table 2 – Signs and symptoms of thiamine deficiency / Wernicke-Korsakoffs Syndrome (WKS) (Thomson et al., 2012)

Signs and symptoms of thiamine deficiency/WKS
Early signs and symptoms: • Loss of appetite • Nausea/ vomiting • Fatigue, weakness, apathy • Giddiness, diplopia • Insomnia, anxiety, difficulty in concentration • Memory loss
Later signs and symptoms: • Classic triad: oculomotor abnormalities, cerebellar dysfunction (ataxia) and confusion • Quiet global confusion with disorientation in time/ place • Confabulation/ hallucination • Onset of coma
Operational criteria for Wernicke's Encephalopathy (Caine et al., 1997): 2 of the following: • Dietary deficiencies • Oculomotor abnormalities • Cerebellar dysfunction • Either altered mental state or mild memory impairment

5.2.2 Other signs and symptoms of ARBD that have been observed in the literature include deficits in long-term memory for experiences (i.e., episodic memory), particularly after the onset of the condition (i.e., anterograde amnesia), impairments of higher-order cognitive skills such as decision making and planning, and behavioural symptoms such as aggression, impulsivity and frequent attendances at hospital (RCP, 2014; Wilson et al., 2012).

5.2.3 Identification of patients with potential ARBD on acute inpatient wards requires a pragmatic approach. The Wirral service has adopted a two-phase process whereby high-risk patients are initially identified by ward nurses or alcohol liaison nurses using general information from the clinical history, and then a more specialist assessment is provided by the ARBD team consultant within five working days. This process is suitable for more acutely unwell patients presenting in the acute hospital setting.

Operational criteria for possible ARBD diagnosis

5.2.4 Wilson and colleagues (2012) have propounded operational criteria for ARBD for use by nurses in acute hospital settings. These criteria are yet to be validated, but could assist in the early identification of those with or at risk of ARBD. If all three of the following criteria are met then referral to specialist ARBD services should be made (see Appendix A for other ARBD diagnostic criteria):

a. Probable drinking history of heavy, long-standing alcohol drinking: 35 units or more a week for at least five years.
b. Confusion, memory problems, doubt about capacity and concerns about risk on discharge, after withdrawal/physical stabilisation.
c. Three or more admissions into hospital and/or Emergency Department in 12 months probably associated either directly (withdrawal, unconscious) or indirectly (trauma organ diseases, etc.) with alcohol ingestion or one or more delayed discharges from general hospital wards in the last 12 months (a delayed discharge is defined as patients staying on the acute medical/ surgical ward because of social and/or psychiatric problems).

Cognitive Screening

5.2.5 Cognitive Screening Instruments (CSIs) are brief tests of cognition that offer an insight into an individual's level of functioning in a variety of areas (e.g., memory, attention etc.). Cognitive screening can be undertaken in a variety of environments (e.g., treatment centres, bedside) by different professionals (e.g., nursing staff, social workers) with little training required, thereby increasing the chances of early identification. A summary of the findings relating to CSIs from Heirene and colleagues' (2018a) recent systematic review of neuropsychological tests used for ARBD assessment is presented below (for a tabulated overview of findings relating to the utility of various CSIs in this domain, see Appendix C).

5.2.6 Both the MoCA (Nasreddine et al., 2005) and MMSE (Folstein, Folstein, & McHugh, 1975) are effective at distinguishing between those with and without

ARBD and between gradations of alcohol-related impairment (providing the cut-off point for impairment is adjusted accordingly), though the MoCA appears the superior of the two (Oudman et al., 2014; Wester, Westhoff, Kessels, & Egger, 2013).

5.2.7 The ACE-III (Hsieh, Schubert, Hoon, Mioshi, & Hodges, 2013) also appears useful as a screening tool for ARBD and provides a more comprehensive overview of cognition while remaining quick to administer (Brown, Heirene, Roderique-Davies, John, & Evans, 2019). The ACE-III is the most frequently used cognitive screening instrument in South Wales for ARBD diagnosis (Heirene et al., 2019; Heirene et al., 2020. See Appendix C for the average ACE-III scores for alcohol-dependent individuals with and without ARBD).

5.2.8 Two new CSIs have recently been developed specifically for assessing alcohol-related cognitive impairments: the Brief Examination of Alcohol-Related Neuropsychological Impairments (BEARNI; Ritz et al., 2015) and the Test of Detection of Cognitive Impairment in Alcoholism (TEDCA; Jurado-Barba et al., 2017). Although both have only been validated in alcohol dependent populations not meeting ARBD criteria (both CSIs can be accessed in the corresponding publications (the BEARNI is currently only available in French). Nonetheless, both have shown sensitivity to mild alcohol-related cognitive deficits in their validation and are more focused on the functions particularly vulnerable to alcohol abuse: memory, executive function and visuospatial processing. These tests do not appear to have been adopted in UK practice as of yet (Heirene et al., 2018; Heirene, 2019).

5.3 Recommendations

5.3.1 Cognitive screening of individuals with a history of significant alcohol use should be routinely undertaken by trained professionals (on at least a quarterly basis if alcohol consumption continues) in clinical and community-based settings to identify those with risk of ARBD. Primary care should consider alcohol in any assessment regarding memory and cognitive function including younger patients.

5.3.2 Health Boards in conjunction with Substance Misuse Area Planning Boards in Wales should commission specialist Alcohol Liaison Assertive Outreach Teams, for patients at risk of, or diagnosed with ARBD.

6. Assessment and diagnosis

6.1 Background

6.1.1 Following screening and initial identification of those displaying signs of ARBD, it is important to undertake more detailed and comprehensive assessments in order to clarify the diagnosis and to exclude other pathologies (e.g., dementias). The most consistent and prominent brain changes in those with ARBD include an increase in cerebrospinal fluid volume, widespread grey matter volume decreases (particularly in the frontal lobes), and reductions in the volume of the corpus callosum, cerebellum, pons, mamillary bodies, hippocampus and thalamus (Harper, 2009; Zahr et al., 2011). Most of these structural changes are thought to occur along a spectrum, with KS at the severe end of brain damage (Zahr et al., 2011).

6.1.2 Modes of assessment commonly used with this population include neuropsychological testing, neuroimaging, and assessments of capacity and activities of daily living. In addition to informing diagnostic decisions, these assessment methods can inform treatment directions.

6.1.3 A recent systematic review identified that certain cognitive deficits (i.e. response disinhibition, impaired higher order executive functions [e.g. planning, problem solving] and long-term memory failures) are associated with a greater risk of relapse in alcohol-dependent individuals and should therefore be the targets of cognitive remediation efforts if identified (Rolland et al., 2018). Similarly, assessments relating to capacity and the ability to undertake activities of daily living have clear implications for treatment options.

6.2 Evidence

Neuropsychological assessment

6.2.1 The evidence underpinning a variety of neuropsychological tests used to assess ARBD has recently been synthesised and discussed in a large-scale systematic review (Heirene, et al, 2016; Heirene et al., 2018). The findings relating to cognitive screening instruments from this review are discussed in Chapter 5 and therefore this section focuses on comprehensive tests of cognition (only a summary of the key findings is presented here; see Appendix C for more details).

6.2.2 **Memory**: The most useful tests of memory identified by Heirene et al. (2018) were the Rivermead Behavioural Memory Test-3 (RBMT-3; Wilson et al., 1989) and the California Verbal Learning Test (CVLT; Delis et al., 1987). Both

tests offer relatively comprehensive assessments of memory and learning and are highly sensitive to alcohol-related memory deficits.

6.2.3 **Executive dysfunction**: Heirene et al. (2018) recommended the Behavioural Assessment of the Dysexecutive Syndrome (BADS; Wilson, Alderman, Burgess, Emslie, & Evans, 1996) as the most useful test for assessing executive function in ARBD. The BADS assesses multiple executive skills in an ecologically focused format and has demonstrated a high level of sensitivity to the cognitive impairments associated with ARBD (Maharasingam et al., 2013; van Oort & Kessels, 2009).

6.2.4 **General intelligence and battery tests**: According to Heirene et al. (2018), the intelligence test with the largest evidence base to underpin its use in ARBD assessment is the Wechsler Adult Intelligence Scale (WAIS; Wechsler, 1958), which is often viewed as the gold-standard assessment of intelligence (Hayes et al., 2016). Since Heirene and colleagues' review, a second battery test has also been evaluated for ARBD assessment and diagnosis: The Repeatable Battery for the Assessment of Neuropsychological Status (R-BANS). Brown et al. (2018) found an optimum cut-off score of ≤83 produced a sensitivity of 89% and specificity of 67% for the R-BANS when comparing those with ARBD (including KS) and alcohol dependent individuals without ARBD.

6.2.5 **Pre-morbid ability**: The final area of neuropsychological assessment concerns the evaluation of pre-morbid ability. That is, an assessment (or estimate) of a person's cognitive ability prior to the onset of ARBD, thereby allowing clinicians to more accurately determine the extent of their impairment. The most commonly used and well-validated method for this purpose is the National Adult Reading Test-Revised (NART-R; Bright, Hale, Gooch, Myhill, & van der Linde, 2016), which assesses a person's ability to recognise and pronounce phonetically irregular words. The test is predicated on the assumption that vocabulary is highly correlated with intelligence and relatively impervious to most forms of brain damage.

6.2.6 Overall, neuropsychological testing offers an effective and relatively inexpensive method of ARBD diagnosis and provides a wealth of information regarding each person's symptomology in a frequently varied condition. However, neuropsychological test outcomes alone provide insufficient evidence for making ARBD diagnoses due to the multiple possible causes of impaired performance on such tests (e.g., head injuries, neurodegenerative diseases, poor pre-morbid functioning etc.). As a result, all neuropsychological test outcomes need to be considered in conjunction with a clinical diagnostic process and any additional assessment outcomes available in order to make

accurate diagnoses. Repeat testing enables the charting of any trends before finalising a diagnosis.

Neuroimaging

6.2.7 Neuroimaging procedures, including Computed Tomography (CT) and Magnetic Resonance Imaging (MRI), are also frequently used in the assessment and diagnosis of ARBD alongside, or in place of, neuropsychological testing. They provide safe, non-invasive methods that allow for the continual monitoring of a person's neurological health throughout the course of their condition (Zahr, Kaufman, & Harper, 2011). MRI, in particular, has been used in research to characterise the neurological damage associated with ARBD, demonstrating widespread structural brain changes.

6.2.8 As with neuropsychological measures, the diagnostic capabilities of neuroimaging for WKS have also been evaluated. Antunez et al. (1998), found the sensitivity of CT imaging for WE was poor, at only 13%. MRI, while considerably more sensitive to WE, had a low sensitivity level of 53% and a high specificity of 93%. The poor sensitivity of imaging to ARBD was further illustrated by Lough (2012), who found 13% of 48 persons with WE had MRI results suggestive of a normal brain. Still, although the diagnostic accuracy of imaging does not approach the levels found for neuropsychological testing, it can be useful in excluding other pathologies (e.g., vascular issues) that could provide alternative explanations for the cognitive deficit observed (Beaunieux, Eustache, & Pitel, 2015). MRI has also proved useful in detecting improvements in brain health in alcohol dependent individuals, including the increase in white matter volume often seen following periods of abstinence (Gazdzinski, Durazzo, & Meyerhoff, 2005; O'Neill, Cardenas, & Meyerhoff, 2001).

6.2.9 Existing radiology protocols state that CT scans should be undertaken initially, followed by an MRI. In clinical practice with this patient group, more information can be derived from an MRI. A change in protocols following consensus dialogue with Radiology Leads across Wales needs to be achieved for ARBD patients in order to save unnecessary radiation of a CT scan for these patients. Change to the existing Radiology neuroimaging protocol is required, to provide an MRI for ARBD patients instead of CT scan in the first instance.

6.2.10 Despite the many benefits of imaging methods, they (like neuropsychological testing) are unable to identify any single sign that can differentiate ARBD from other possible pathologies that share similar features (Sechi & Serra, 2007). Additionally, the use of imaging may be less accessible than cognitive testing

in some locations. Nonetheless, they represent a useful method for the diagnosis and monitoring of ARBD and should be considered when available.

Nutritional assessment

6.2.11 The evaluation of nutritional status plays an important role in ARBD assessment and can be used to assist diagnostic decision making (Sechi & Serra, 2007). Thiamine (vitamin B1) levels, in particular, are the frequent subject of nutritional assessments due to the central role played by a deficiency of the vitamin in the etiopathogenesis of WKS and, as more recent research suggests, all forms of ARBD (Pitel et al., 2011). Galvin et al. (2010) have suggested that the total thiamine in blood should be measured immediately before administration of thiamine supplementation, and that the method of choice for determining thiamine levels should be high-performance liquid chromatography analysis. However, it should be noted that normal or even elevated levels of thiamine should not be used as a criterion for the exclusion of WE as depletion can be transient (see Lough, 2012).

Assessment of Activities of Daily Living (ADL)

6.2.12 In their review of the literature surrounding ARBD assessment, Horton et al. (2015) found only one study (Irvine & Mawhinney, 2008) that assessed ADLs in those with the condition using the Life Skills Profile (LSP). The LSP is an observational scale completed by an informant involved in the care of the person and focuses on five areas: self-care ability, social contact, communication, responsibility and anti-social behaviour. The scale is strengths-based, focusing on what individuals are capable of doing, and may therefore provide useful information to inform treatment options and track their effects on important indicators of behavioural and social function. The Bristol ADL is also a useful tool in capturing the main areas of ADLs.

Other considerations in ARBD assessment and diagnosis

6.2.13 Assessment of mental capacity is broadly defined as the ability of a person to make a decision (see chapter 7).

6.2.14 Research suggests a number of other relevant considerations should be made in relation to when assessments are implemented and how outcomes should be interpreted. One of the foremost considerations is the point at which neuropsychological tests are administered. A review by Walvoort, Wester, and Egger (2013) found it requires six weeks of abstinence before reliable neuropsychological performance can be achieved.

6.2.15 Repeat testing is also required to monitor cognition over the course of treatment. The Royal College of Psychiatrists (2014) have recommend that

following initial assessments, more detailed cognitive assessments should be undertaken after three months, then repeated at six month intervals for three years. If using repeat testing, it is important to consider the role practice effects have on test performance (Horton et al., 2015) and use parallel versions of tests if available to minimise such effects. See sections 7 and 8 for further information about the stages of assessment.

6.2.16 When interpreting the outcomes from neuropsychological or neuro-radiological assessment, it is also important to consider the effects of any potential comorbid disorders on neurocognitive health. For example, a variety of psychological conditions are known to have deleterious effects on cognition, including depression (Bosaipo, Foss, Young, & Juruena, 2017), attention deficit disorder (Dobson-Patterson, O'Gorman, Chan, & Shum, 2016) and schizophrenia (Bora & Pantelis, 2015), warranting a consideration of any co-existing psychopathology.

6.2.17 The presence of cerebrovascular disease and traumatic brain injuries should also be considered during assessment due to their high prevalence (25%) within the ARBD population (Wilson et al., 2012).

6.2.18 While neuropsychological testing, neuroimaging and evaluations of nutritional status can inform diagnosis, they must be combined with clinical examination to make accurate diagnoses and avoid misdiagnosis. Indeed, the most efficient method for the early identification of WKS has been said to be careful clinical observation, particularly in situations where malnutrition may be suspected (Sechi & Serra, 2007). Following clinical suspicion, the diagnostic approaches discussed above can be used effectively to confirm or deny the diagnosis (Scalzo, Bowden, & Hillbom, 2015).

6.3 Recommendations

6.3.1 All medically-managed alcohol withdrawals should be undertaken in line with NICE clinical guidance and as part of a planned care pathway, in conjunction with local addiction specialist services and recorded on the patient management system within the clinical alcohol services.

6.3.2 Cognitive screening of individuals with a history of significant alcohol use should be routinely undertaken by trained professionals (on at least a quarterly basis if alcohol consumption continues) in clinical and community-based settings to identify those with risk of ARBD. Primary care should consider alcohol in any assessment regarding memory and cognitive function including younger patients.

7. Pathways for Assessment and Treatment

7.1 Background

7.1.1 The variability and the various syndromes within ARBD brings about clinical challenges in the areas of recognition, screening, assessment, having appropriate treatment pathways in healthcare and non-healthcare settings and the longer term rehabilitation needs (depending on the clinical syndromes).

7.1.2 Whilst dealing with the various syndromes in ARBD, the cognitive impairment may have an impact on an individual's awareness and understanding of their circumstances, and equally may have implications for understanding and being concordant with the interventions. This may have legal implications in that a comprehensive assessment of the individual's capacity to make decisions and the subsequent use of the Mental Capacity Act 2005 may become important.

7.1.3 The RCP report on ARBD (2014) highlights a paucity of evidence based clinical guidelines for the management of ARBD which is reflected in organisational and commissioning issues e.g. rarely does a single Mental Health speciality take responsibility for this group of patients (Leenane, 1986; Price et al, 1988); there is a lack of diagnostic awareness and expertise within psychiatry, medical and nursing staff; few existing pathways of assessment and care; stigma and lack of resources. This often results in this patient group being "passed from pillar to post".

7.1.4 In tackling the problem of ARBD and working through the maze of all syndromes with wider diagnostic, treatment, legal, commissioning and funding issues, evidence from specialist ARBD services has begun to highlight that with clinically validated assessment tools, early identification of ARBD with pharmacological, psychosocial interventions and having a rehabilitative model, ARBD – contrary to the popular myth – is a non-progressive condition.

7.2 Evidence

Primary Care

7.2.1 In order to prevent and manage ARBD, use of NICE recommended tools becomes crucial right from the first point of contact with the health services. To reduce the risk of alcohol-related withdrawals and further cognitive damage, medically assisted withdrawals should be offered as per the NICE (2011, Chapter 1) guidelines:

"For service users who typically drink over 15 units of alcohol per day and/or who score 20 or more on the AUDIT, consider offering an assessment and delivery of community based assisted withdrawal or assessment and management in specialist alcohol services if there are safety concerns about the community based assisted withdrawal."

7.2.2 In addition to the assessment and management as per NICE guidelines within Primary Care, nutritional assessments and vitamin supplementation at an early stage is more likely than not to prevent further damage. Whilst there remains some concerns within Primary care settings in relation to the provision of parenteral intramuscular (IM) Pabrinex® based on concerns of anaphylaxis, there is sufficient evidence, including that provided by The Committee on the Safety of Medicines, British Association for Psychopharmacology, National Addictions Centre at Kings College, and NICE, to highlight that the benefit to risk ratio favours the use of parenteral thiamine.

7.2.3 The recent Healthcare Inspectorate report (2018) have reflected a lack of clinical consistency in recognising and hence assessing and managing alcohol-related problems within Primary Care in Wales.

Specialist Substance Misuse Treatment Services

7.2.4 NICE guidelines (2011) recommend that all patients referred to alcohol treatment services should have a cognitive assessment. It is well recognised that individuals who present to alcohol services for medically assisted withdrawal or detox programmes may have raised blood-alcohol levels and as a direct consequence, an effect of alcohol-related decline in cognitive performance.

7.2.5 Longer term cognitive dysfunction can only be assessed after 60 days of abstinence (Oslyn and Kerry, 2003).

7.2.6 Tools such as MoCA or ACE 3-R can be considered earlier on in the medically assisted withdrawal programmes for this cognitive assessment (see Chapter 6). Patients with a higher risk of developing thiamine deficiency related brain damage – high risk drinkers, low BMI, patients missing regular meals and those with a long history of alcohol misuse, should be prescribed parenteral thiamine prophylactically and during the medically assisted withdrawal interventions.

7.2.7 After the detoxification, emphasis on a longer-term treatment plan with regular cognitive assessments, maintenance of abstinence, nutritional and psychosocial support along with assessment of capacity to engage in treatment programmes needs to be considered.

7.2.8 Alongside the pharmacological, nutritional and psychosocial support, a number of neuropsychological and cognitive rehabilitative approaches have shown to be beneficial and can be considered such as errorless learning, assisted technology, enhancing executive functioning, mood modification and memory cueing (see Chapter 8 for further evidence on rehabilitative approaches).

Legal Framework and ARBD – Mental Capacity Act

7.2.9 The interface issues of addiction, ARBD, the Mental Capacity Act, 2005 (MCA) and the Mental Health Act 1983 (MHA) are complex. Whilst addiction per se does not fulfil the criteria for the use of the MCA, ARBD as a diagnostic syndrome does. The large majority of people with ARBD of any severity may present primarily with cognitive damage which has implications on their capacity to understand and engage with the Treatment Programmes.

7.2.10 Whilst the MHA may be used for ARBD, the practical challenges from clinical experience and data from Cwm Taf Morgannwg University and Aneurin Bevan University Health Boards on the use of the MHA highlights that the MHA is generally not used in Wales for ARBD. However, assessing the capacity of individuals with alcohol-related problems becomes important in acute hospital settings as well as in community settings after having achieved acute physical stabilisation.

7.2.11 Use of the MHA would be appropriate for the management of any co-occurring mental health problems or for the medical management of symptoms directly associated with the ARBD (such as extreme distress/agitation). Such treatment would generally be provided on mental health inpatient wards. In some instances, it is more appropriate to consider the use of MCA; for example, in the management of physical health problems or where decisions about care and support or accommodation are being made.

7.2.12 The two principle cognitive domains affected in ARBD are memory and reasoning, and deficits in these areas will affect decision-making in a number of ways:

- Short term memory deficits – the individual may struggle to register, retain and recall the information.
- Long term memory deficits – ARBD sufferers can have up to 20 years retrospective memory loss and may, therefore, have no significant memory nor understanding of how their alcohol misuse has contributed to the current situation.
- Reasoning problems – these are often subtle but more common than the memory difficulties. They may not be obvious but will have a profound

effect on their ability to understand and weigh up the pros and cons of different decisions.

7.2.13 When assessing capacity in individuals with ARBD, it is important to consider the following factors:

- Give all the relevant information. Are they aware of their alcohol problem and the issues they are facing? If they do not know, then tell them and encourage learning e.g. by repetition, summarising etc.
- Make sure they can remember the information. Ask them to repeat/summarise. Get care staff to reinforce the information after your initial assessment. Give written information tailored to their needs. Revisit a couple of hours/days later and test recall.
- Check understanding. Do they know what is wrong? Do they know what they need help with? Do they know the role alcohol has placed in their problems?
- Check their reasoning and "weighing up". What do they think the pros and cons of the proposed support/intervention are? What weight do they give to the different pros and cons? What would be the risks if they don't have the support?

7.2.14 It is important not to assume a lack of capacity unless the relevant information has been presented in a suitable format to the individual and they have been supported as much as possible to make the decision. Equally, however, it is important not to withhold the support and protection of relevant legislation to those lacking in capacity to make decisions about care simply because the particular nuances of capacity assessment in ARBD have not been considered.

7.2.15 MCA facilitates the assessment of the individual's capacity to make decisions and is based on the five principles of:

- Presumption of capacity.
- Individuals to be supported to make their own decisions.
- A person is entitled to make an unwise decision
- Best interest – all actions and decisions must be in the *person'*s best interests.
- Using least restrictive options.

7.2.16 When assessing capacity under the MCA, it is important to understand that the assessment of capacity has to be done by the decision maker, where the decision maker is the person who is deciding whether to take action in

connection with the care or treatment of an adult who lacks capacity or who is contemplating making a decision on their behalf:

- Where the decision involves medical treatment – the doctor proposing the treatment is the decision maker.
- When nursing care is provided, the nurse is the decision maker.
- For most day-to-day actions or decisions, the decision maker will be the person who is most directly involved with the person at the time.
- Outside hospital, this is most likely to be social workers, care workers and family members. Most people have the capacity to make most decisions themselves.

7.2.17 When assessing a person's capacity to make a time and issue-specific decision, practitioners should refer to the statutory Code of Practice to the MCA which sets out specific guidance on assessing mental capacity, best interest decision-making and the role of the IMCA.

7.2.18 Further whilst determining capacity, a *two-stage test of capacity* must be followed:

Diagnostic test- This answers the question "is there an impairment of, or disturbance in the functioning of persons mind or brain" followed by a ***functional test*** which answers the question "is the impairment or disturbance sufficient that the person lacks capacity to make that particular decision".

Whilst looking at the ***functional test***, four areas need to be fulfilled for a person to be deemed to have capacity and these include:

- The ability to understand the decision.
- The ability to retain information about their decision.
- The ability to use and assess information about the decision.
- The ability to communicate their decision.

If a person lacks function in any **one** of these areas, then this represents a lack of capacity.

7.2.19 When capacity is assessed it is important that it is decision specific. If the person lacks capacity in relation to that specific decision, a Best Interests Decision must consider the individuals wishes and the least restrictive option.

7.2.20 The use of MCA is also relevant in clinical practice when dealing with people who express or demonstrate lack of motivation/denial of alcohol problems. For most people with alcohol dependence, denial has a psychological basis and can be best conceptualised as a defence mechanism. However, in

individuals with alcohol-related cognitive impairments, denial can have a cognitive basis. The latter reflects an issue of capacity and needs to be considered under the MCA.

Commissioning of Services

7.2.21 The absence of well-established clinical guidelines, lack of expertise and other factors highlighted earlier implicate that commissioning of services for ARBD in Wales has not been a priority to date.

7.2.22 Commissioning services for ARBD need to augment the integration of current services based on evidence from different service models, summarised in Table 3**.**

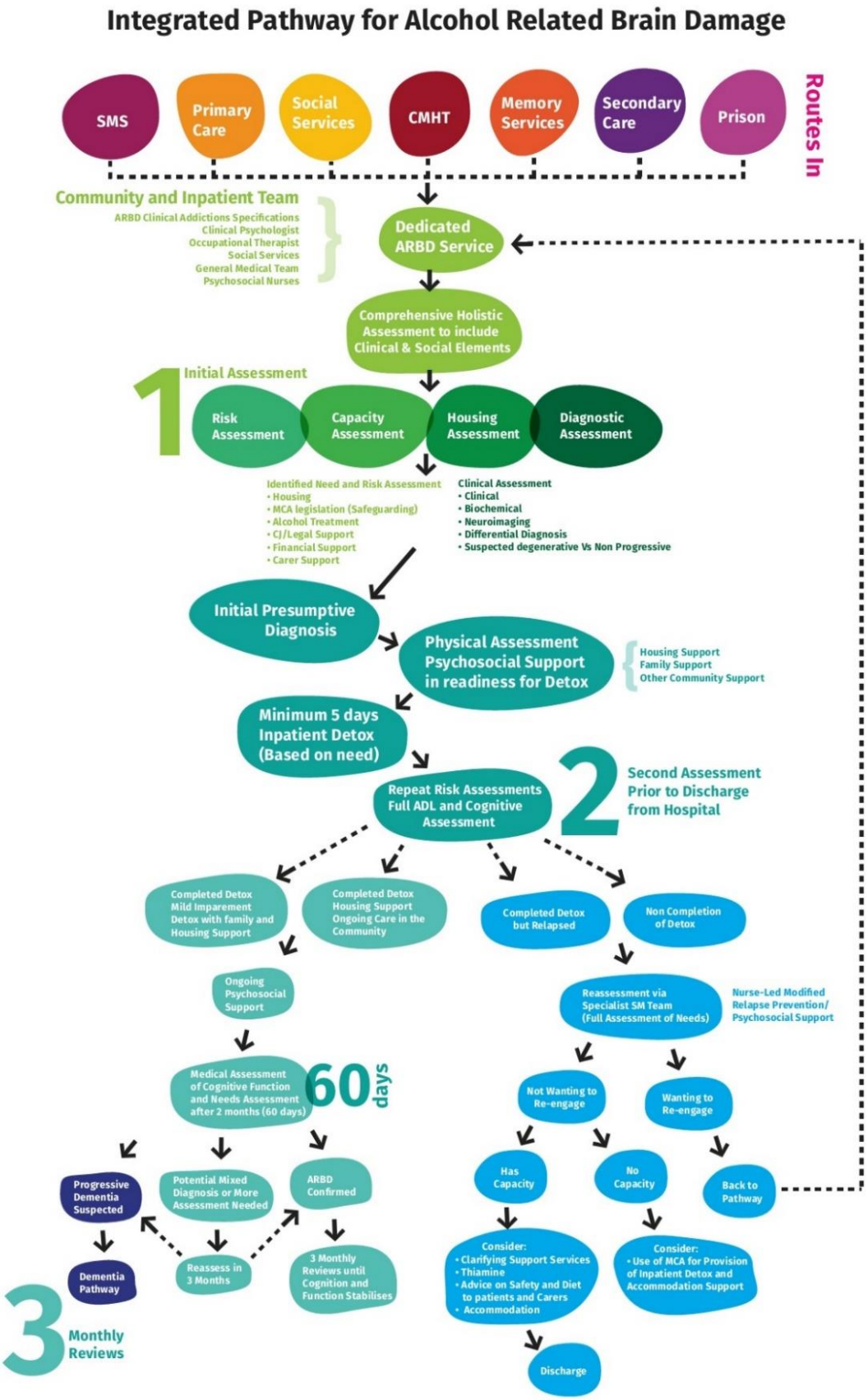
7.2.23 Social Services undertake assessments with, and commission care packages for, many individuals with ARBD as in some areas they are considered ineligible for health funded placements. This is not reflected in Table 3.

Table 3 - Commissioning for ARBD- Adapted from CR185 (Royal College of Psychiatrists, 2014)

Service Model	**Advantages**	**Disadvantages**
Single/dedicated service	- Deliver totality of care and rehabilitation - Access to a range of service provisions - Significant experience for management of people with Cognitive Impairment NHS- Neuropsychiatry services are best suited for this model	- Few Comprehensive Neuropsychiatric services for ARBD Private organisations fill in gap- No Standardisation and Effectiveness can be variable, often 'out of area' with variable costs & lack of integration with NHS – Health and social care
ARBD Services within Health Boards (for Wales)	- Specific ARBD commissioned services within NHS - Access to wider institutions and services for rehabilitation - Individual/Person-Centred Care Packages	- Time constraints due to personalised packages Evidence of effectiveness in higher prevalence areas

Service Model	Advantages	Disadvantages
	Better integration within Health and Social Care	
Specialist services embedded within Generic Teams	- Specialists led - Increase in expertise of the generic team Scope of integration with Health and Social care	- Possibly best for low prevalence areas No current services like this in UK
Single/dedicated service	- Deliver totality of care and rehabilitation - Access to a range of service provisions - Significant experience for management of people with Cognitive Impairment NHS- Neuropsychiatry services are best suited for this model	- Few Comprehensive Neuropsychiatric services for ARBD Private organisations fill in gap- No Standardisation and Effectiveness can be variable, often 'out of area' with variable costs & lack of integration with NHS – Health and social care
ARBD Services within Health Boards (for Wales)	- Specific ARBD commissioned services within NHS - Access to wider institutions and services for rehabilitation - Individual/Person-Centred Care Packages Better integration within Health and Social Care	- Time constraints due to personalised packages Evidence of effectiveness in higher prevalence areas
Specialist services embedded within Generic Teams	- Specialists led - Increase in expertise of the generic team Scope of integration with Health and Social care	- Possibly best for low prevalence areas No current services like this in UK

Clinical care pathway for ARBD



7.3 Recommendations

7.3.1 Establishment of dedicated ARBD Services within each Health Board, with ARBD clinical specialists, clinical psychologists, occupational therapists, social services and general medicine and timely access to treatment and care.

7.3.2 Establishment of regional inpatient centres of excellence for ARBD to support appropriate diagnostic assessment, research and evaluation on clinical and service delivery models.

7.3.3 In line with NICE, the Royal College of Physicians and the British Association for Psychopharmacology recommendations, Thiamine, both parenteral Pabrinex® and oral Thiamine should be available and prescribed as clinically indicated.

8. Treatment and support provision

8.1 Background

8.1.1 Few dedicated services currently exist across the UK for the management of ARBD and, as a result, patients may be placed within a range of different service types such as adult mental health services, memory services and alcohol treatment services. Alcohol services may meet some of their needs but struggle to engage those with cognitive impairment. Older adult mental health services can provide longer term care for those with permanent cognitive impairment but many people with ARBD are younger than their threshold age (often 65) and these services generally do not have the expertise to deal with alcohol misuse (McCabe, 2006). As a result patients can find themselves placed between services with disagreement over which service should take the lead.

8.1.2 Where specialist services do exist (both community and residential), it is possible to provide tailored cognitive rehabilitation alongside supportive alcohol treatment programmes, delivered by staff with knowledge and skills in the management of ARBD (Cox et al, 2004).

8.2 Evidence

8.2.1 The key principles associated with the psychosocial rehabilitation of patients with ARBD are:

- Prioritisation of abstinence.
- A rehabilitative approach to activities of daily living.
- Active family engagement.
- Multidisciplinary management (North et al, 2010).

8.2.2 Patients with ARBD tend to present in one of two ways:

- Acute presentation, often within the general hospital setting, with acute confusion arising from alcohol withdrawal and possible intercurrent illness.
- Chronic presentation in the community with a history of gradual cognitive decline.

8.2.3 The five stage model (Wilson et al, 2012) outlined below provides the basis for action. With assertive follow-up of patients on the five-stage treatment model, relapse into alcohol misuse is 10%, mortality is 10% and there is an observed 85% reduction in hospital readmission rates.

Table 4: Five Stage Model of Alcohol-Related Brain Damage (Wilson et al, 2012)

Stage	Focus of Treatment	Average Duration
1. Acute Medical Stage	Physical stabilisation and withdrawal from alcohol	Days-weeks
2. Acute Global Confusion	Psychosocial assessment	2-3 months
3. Non-permanent Cognitive Dysfunction	Therapeutic rehabilitation	Up to 3 years
4. Transition Stage	Adaptive rehabilitation	Variable
5. Permanent Cognitive Dysfunction	Social integration and relapse prevention	Ongoing

8.2.4 Patients presenting acutely will often be seen within Stage 1 but those presenting in the community may be seen at any stage. In such cases, a robust assessment is vital to ensure that interventions are tailored to the appropriate stage. Not all individuals will progress through all five stages – some will regain near normal cognitive function in Stages 2 or 3; hence it is vital to develop flexible care plans that can adapt to potential improvements.

Acute Medical Stage – Physical Stabilisation and Withdrawal from Alcohol

8.2.5 The main focus for this stage is to ensure patient safety, stabilise any coexisting medical conditions and appropriately manage alcohol withdrawal in line with national guidance (NICE, 2017). Most cases will be managed within the acute hospital setting and the initial priority is the physical health of the patient and will often include the use of high dose, parenteral thiamine. Once the physical condition has stabilised, a more in-depth assessment should be made and would appropriately include past history of alcohol consumption/treatment for alcohol-related problems, a corroborative history to clarify functional evidence of cognitive impairment and confabulation and any information that would contribute to care planning and eventual discharge (MacRae & Cox, 2003). As part of this process it is important to consider the assessment of mental capacity and to develop an appropriate risk management plan.

8.2.6 Assessments of cognitive function should form part of the initial assessment of all patients with alcohol use disorders and should be repeated as part of the

ongoing monitoring process of those with ARBD (Royal College of Psychiatrists, 2014).

8.2.7 It is important to combine cognitive testing with a clinical diagnostic process that includes investigations to rule out alternative or additional intracranial pathology (Oslin & Carey, 2003) and a more in-depth neuropsychological/psychosocial assessment to guide a targeted treatment approach.

Acute Global Confusion – Psychosocial Assessment

8.2.8 During this phase improvements will be noticed for a significant proportion of patients as long as they are able to remain abstinent from alcohol. The rate and extent of the improvement will depend upon the levels of underlying brain damage as well as any co-occurring physical or mental health problems. Some patients can be discharged back to their home environment during this stage, but some may require a higher level of support (e.g. residential care, supported accommodation). Abstinence should be prioritised, and involvement of specialist alcohol treatment services should occur at an early stage, although standard treatment approaches may need to be adapted to take account of levels of cognitive impairment (MacRae & Cox, 2003). If the patient is unable to make informed decisions about abstinence as a result of impairment of memory and decision-making, consideration should be given to the use of the MCA to provide appropriate protection.

8.2.9 The Acute Global Confusion stage has five major therapeutic themes:

- Normalisation – to include good nutrition, mood stabilisation, regularisation of sleep pattern (Malloy et al, 1990) and strengthening of family relationships (Yivisaker & Feeney, 1998; Jacques & Anderson, 2002).
- Developing a therapeutic relationship – with key members of the care team.
- Orientation – mainly with respect to time but may need orientation for place and person.
- Memory support – strategies to support memory function can be introduced at this stage (see below) (Baddeley et al, 2002).
- Continual assessment – to ensure that the care plan and risk management plan remain tailored to the patient's need as cognitive function improves.

Non-permanent Cognitive Dysfunction – Therapeutic Rehabilitation

8.2.10 Some patients will recover significantly during Stage 2 and not progress to Stage 3. For those who do, targeted rehabilitation can continue to produce improvements in cognitive function for up to three years. This stage should be underpinned by robust care planning and a strong relationship with the

coordinator of care, who should be an experienced clinician with appropriate knowledge and skills in relation to ARBD. The care plan should be regularly reviewed and adapted to changing needs during this stage and there are a number of issues that need to be considered within the care plan:

- Developing autonomy.
- Promoting functional recovery.
- Orientation and memory support.
- Impulse and behaviour control.
- Managing apathy and motivation.
- Managing alcohol.
- Developing relationships.

8.2.11 Formal monitoring of progress should continue throughout this phase with cognitive testing typically being repeated every six months to ensure that interventions remain appropriate to patient need (Royal College of Psychiatrists, 2014).

8.2.12 Evidence to support specific cognitive interventions in ARBD is not strong but there is support for general treatment approaches (Svanberg & Evans, 2013). As has already been stated, all approaches are enhanced by tailoring them to the specific needs of the patient and, as such, a comprehensive, flexible care plan is vital (Fals-Stewart & Lucente, 1994).

Orientation and Memory Support

8.2.13 Interventions found to be effective in this stage are derived from descriptive research conducted in patients with acquired brain injury as well as ARBD (Bates et al, 2002; MacRae & Cox, 2003). Allowing more time for interventions, giving patients greater explanations and encouraging them to explain the concepts presented to them, increases subsequent recall (VanDamme & d'Ydewalle, 2008). There is also evidence that 'errorless learning' improves recall (Kessels et al, 2007). In errorless learning the patient is asked to repeat information immediately after it has been presented, reducing the amount of 'guesswork' which would otherwise simply repeat incorrect information. The use of diaries and electronic reminders helps with attendance at appointments (Baddeley et al, 2002) and providing structured rules improves problem solving abilities (Bardenhagen et al, 2007).

Supporting Abstinence from Alcohol

8.2.14 Traditionally abstinence from alcohol is supported by both psychosocial and/or pharmacological interventions delivered as part of relapse prevention programmes (NICE, 2011). Relapse prevention medication requires informed consent before it can be commenced and must be taken regularly. Cognitive

impairment can affect a patient's capacity to consent to medication and their ability to observe a regular dosing regimen. Standard relapse prevention counselling relies on a degree of cognitive flexibility and abstract thinking that individuals with ARBD may find difficult. That is not to say that relapse prevention strategies cannot be used in patients with ARBD but that standard approaches will need to be tailored to the cognitive needs of the patient.

8.2.15 It is important to introduce educational material about the effects of alcohol when cognitive function has improved to a suitable level. Even then, individuals with cognitive impairment will take longer to benefit from interventions and may need more frequent sessions (McCrady & Smith, 1986). Presenting information repeatedly in a variety of formats (e.g. written, verbal, pictorial) may also help (Royal College of Psychiatrists, 2014).

Treatment of Co-occurring Conditions

8.2.16 Many patients with alcohol problems present with co-occurring physical and mental health disorders. In themselves these can contribute to the apparent level of cognitive impairment (e.g. poor motivation in depression, intermittent confusion in hepatic impairment). It is important, therefore, to ensure that these are treated as part of the overall management of ARBD (Lingford-Hughes et al, 2012).

Transition Stage – Adaptive Rehabilitation

8.2.17 Within Stage 3 the patient will ultimately reach their optimum level of recovery and, as their improvements plateau, Stage 3 will blend into Stage 4. During the transition stage it is important to reassess the patient's functioning and the amount of support they require to live as independently as possible. A full occupational therapy assessment is recommended at this stage so that any necessary adaptations to the home environment can be made.

8.2.18 Often Stage 4 involves the transfer of the patient from a residential setting to a more independent one such as supported living or to a home environment with care packages. It is important that such transfers of care are adequately planned to ensure that the skills gained in Stage 3 are transferred to the new environment and that the new carers can be trained and supervised in supporting them.

Permanent Cognitive Dysfunction – Social Integration and Relapse Prevention

8.2.19 The two main therapeutic principles of this stage are to prevent relapse into alcohol misuse and to maintain an optimum level of independence and quality of life over the long term. The aim is to support the patient to live in the least restrictive environment with whatever level of cognitive impairment remains.

Relapse prevention interventions will need to be tailored to the specific abilities and needs of the patient and may require specialist workers to deliver them. Structured activities and weekly routines help to promote long term independence and prevent relapse (Department of Health, 2006).

8.3 Recommendations

8.3.1 Establishment of dedicated ARBD Services within each Health Board, with ARBD clinical specialists, clinical psychologists, occupational therapists, social services and general medicine and timely access to treatment and care.

8.3.2 Establishment of regional inpatient centres of excellence for ARBD to support appropriate diagnostic assessment, research and evaluation on clinical and service delivery models.

9. Support for ARBD patients who are non-abstinent

9.1 Background

9.1.1 The cognitive impairment of ARBD is likely to worsen with continued drinking and abstinence is, therefore, the main goal of treatment. However, some patients choose to continue to drink and are often automatically excluded from services as a result. Guidelines on the management of ARBD tend to assume abstinence and there is a lack of guidance on how to manage those unwilling or unable to achieve this.

The decision-making process

9.1.2 In British law, adults without any impairment of capacity are allowed to make their own decisions regarding alcohol consumption, even when these decisions might seem unwise to others. Before accepting these decisions, however, professionals need to be assured that two factors have been fully explored:

- The patient has received an appropriate assessment of their capacity to make that decision.
- The patient has been given all the information they require, in a form they can easily understand, in order to be able to make the decision.

9.1.3 Some patients and health/social care professionals are unaware that ARBD can improve with abstinence. This can lead to a misguided attitude of “they might as well carry on drinking” which then denies the patient the opportunity to improve their condition. Staff working with this patient group need to be fully aware of the facts of alcohol related harm so that they can provide patients with accurate information, enabling them to make an informed decision.

9.1.4 The cognitive impairment of ARBD is such that patients may need to be presented with this information in a modified way. The use of easy to read, engaging PILs and providing information in short, repeated sessions, involving significant others where possible, will improve the understanding and retention of information (McCrady & Smith, 1986). If, despite such measures, it is clear that the patient cannot use the information in order to make a reasoned decision, then the appropriate process under the MCA should be followed (see Chapter 7).

9.1.5 Denial, of varying degrees, is a common accompaniment to alcohol dependence and functions as a natural defence mechanism. However, it is important to differentiate between this and the inability to retain, process and/or weigh up information as a result of brain damage (Rinn et al, 2001). An individual with short term memory problems may make a certain decision during a conversation with a professional yet, within an hour, be unable to

recall the decision they have made. When assessing the capacity of an individual with ARBD to make decisions about continued drinking, it is important to assess their recollection of their personal drinking history and its related problems, which can influence their understanding of their current situation.

Those refusing input from services

9.1.6 Some patients with ARBD who are assessed to have full capacity to make decisions about their drinking and who wish to continue to drink, may also refuse to engage with alcohol treatment services. Before discharge, the following must be considered:

- Does the individual fully understand what treatment services can offer and that a harm reduction approach (as opposed to total abstinence) can be supported?
- Are they being prescribed thiamine supplements?
- Has safety advice been given to the patient and their carers?
- Has advice on diet been provided?
- Has the patient been supported to find appropriate accommodation if necessary?

9.1.7 Alcohol Change UK's Blue Light Manual[8] offers practical advice on ways to work with drinkers who do not show clear motivation to engage with services, and sets out positive strategies that can be used with this client group. The manual is available on the charity's website.

Those willing to engage with services

9.1.8 Some patients with ARBD who choose to continue to drink, may be willing to engage with services (both alcohol treatment services and wider support services). It is important that services do not exclude patients who are not initially focussed on achieving abstinence and are willing to work within a framework of harm reduction. Even though patients with ARBD have cognitive deficits, it is possible to deliver harm reduction interventions as long as they are modified to take into account their specific areas of impairment. This underlines the importance of comprehensive assessments of cognitive function, with the gold standard being a full neurocognitive assessment. Tailoring the approach to the specific pattern of cognitive deficits experienced can be highly effective in helping the patient understand their condition and the implications of continued drinking.

[8] Alcohol Change UK. Blue light manual

9.1.9 Stigma still exists in some services towards patients with ARBD. Although they experience problems with mental health, cognition and alcohol, the presence of each one can be used as an exclusion criterion for them engaging with services aimed to address the others (e.g. alcohol treatment services feeling that they cannot deliver interventions to patients with cognitive impairment; mental health services feeling that they cannot work with patients who are drinking) (Rinn et al, 2001). In reality there is a lot that can be achieved particularly if the services work together to support the patient and one another. In all cases this is assisted by the existence of a comprehensive care plan shared by all services and the patient.

9.2 Evidence

Accommodation

9.2.1 Stable accommodation is an important factor in supporting individuals with alcohol related impairment. For patients with ARBD, varying levels of supportive accommodation may be required for different patients and also for the same patient over time (as their condition either deteriorates or improves). Comprehensive accommodation provision should include:

- Support to live independently in the community.
- Support for carers where patients are living with significant others.
- Supported living (shared houses or flats).
- Residential facilities (specialist or general care homes).
- Nursing homes (specialist or general).

9.2.2 Traditionally supported living and residential/nursing facilities require abstinence from alcohol as precondition for tenancy. This can lead to vulnerable individuals being unable to access safe accommodation because of their difficulties controlling their alcohol intake. There is debate amongst some professionals as to the effectiveness of promoting complete abstinence within a group that find abstinence difficult to attain and, as such, specialist units often choose to take a harm reduction approach.

9.2.3 A study conducted by the University of Stirling considered the knowledge and attitudes of staff working in residential homes where patients with ARBD were accommodated. They found that staff often held inaccurate beliefs around the implications of continued drinking for patients with ARBD and that this, in turn, influenced abstinence policies within the homes. This study highlighted the importance of education for care workers so that decisions around placement

and continued drinking are made in a person-centred way and not based on the beliefs of staff.

9.2.4 In Australia, the Wintringham Project is a specialised model of residential care where residents are not required to be abstinent and can access a variety of treatment options. It arose from the observation that older people with ARBD are less likely to see an improvement in cognitive deficits with abstinence (Rota-Bartelink & Lipman, 2007). The model has been criticised however because of the fine balance between supporting resident autonomy and providing adequate levels of protection from ongoing harm.

9.2.5 Research suggests that a significant cohort of patients with ARBD exists within the UK homeless population. A Scottish study assessed 266 homeless people from three hostels in Glasgow and estimated the prevalence of ARBD within that population to be around 21% (Gilchrist & Morrison, 2005). This is a population unlikely to present directly to treatment services, as they tend to lack the social and family support networks seen with other patients with ARBD.

9.2.6 An assertive outreach approach will help to pick up undiagnosed cases and ensure that these patients are provided with all the relevant information they require in order to make treatment decisions. It is important that those who choose to continue to drink, can access the same support services as patients in accommodation. An important part of this support is helping the individual to access appropriate accommodation if this is what they choose to do.

Thiamine supplementation

9.2.7 A discussion of the value of thiamine supplementation in individuals with ARBD who achieve abstinence has already been outlined in Chapter 4. However, little has been written about the value of thiamine supplementation in those who continue to consume alcohol.

9.2.8 A continuous supply of thiamine is required for full brain function and, at normal plasma concentrations, thiamine enters the brain via a high affinity, carrier mediated process. Under normal circumstances the rate at which thiamine crosses into the brain matches the rate of its utilisation within brain tissue. As such the brain is very vulnerable to falling blood levels of thiamine (Greenwood et al, 1980; Greenwood & Pratt, 1982; Rindi et al, 1980). Passive diffusion across the blood-brain barrier can occur but requires concentrations of thiamine probably not achieved by oral administration in malnourished, alcohol-dependent patients (Thomson et al, 2002).

9.2.9 A study of abstinent, previously alcohol-dependent subjects suggested that blood thiamine levels were selectively related to memory performance in this

group (compared to controls without a history of alcohol dependence with similar thiamine blood levels) (Pitel et al, 2011). This finding supports the importance of maintaining an adequate circulating level of thiamine in order to reduce the risk of developing memory impairments. This then has practical implications for the consideration of thiamine prophylaxis in patients presenting to treatment services, as distinct from the treatment of established WE or prophylaxis during planned alcohol detoxification.

9.2.10 Patients with an established diagnosis of ARBD would clearly meet the criteria by virtue of the diagnosis alone, but would generally exhibit other risk factors in addition (particularly homeless patients), clearly qualifying them for the use of parenteral thiamine during alcohol withdrawal.

9.2.11 Even patients with ARBD who wish to continue drinking may experience unplanned episodes of alcohol withdrawal. Some of these will be monitored medically (e.g. an emergency admission because of a head injury) whereas others will be completely ad hoc (e.g. enforced withdrawal due to poor management of finances secondary to dysexecutive syndrome). It can be argued, therefore, that individuals with ARBD are at constant risk of the development of complicated alcohol withdrawal including WE, which would then add to the burden of their cognitive impairment.

9.2.12 Although no formalised trials exist, services have developed the practice of providing parenteral courses of thiamine to those with ARBD who continue to drink in the community to guard against the additional cognitive burden of unplanned withdrawals. These courses are provided alongside an ongoing prescription of oral thiamine. Although no formalised human trials have been carried out, animal models have shown that the brain damage caused by alcohol appears to be more severe in the presence of thiamine deficiency and that recurrent periods of thiamine deficiency cause cumulative brain damage (Crowe & El-Hadj, 2002; Price et al, 1988; Ciccia & Langlais, 2000). Some authors, therefore, conclude that alcohol dependent patients should be given prophylactic thiamine as a matter of course, orally or parenterally, to help protect the brain during periods of detoxification or whenever they present to medical services (Tomson et al, 2012).

Physical health

9.2.13 Individuals who have a history of alcohol misuse sufficient to cause brain damage, are highly likely to have developed additional organ damage. Alcohol can damage virtually every organ system in the body, and it is important that alcohol-dependent patients have their physical health reviewed. The cognitive impairment of ARBD may mean that patients find it difficult to keep

appointments and so every effort should be made to help them attend (including the use of home visits and assertive outreach).

9.2.14 Dependent drinkers often neglect their nutrition. As a result, they may experience other nutritional deficiencies aside from thiamine. A good assessment of nutritional status is important as is the use of methods to improve food intake such as mealtime prompting.

9.2.15 Ongoing alcohol dependence should not be an exclusion criteria for access to health services and supportive care and so it is important that relevant services receive education on ARBD to help them understand how the cognitive deficits can impact on engagement.

Mental health

9.2.16 Many patients with ARBD have co-occurring mental health problems and it is important to manage this as part of the overall treatment with ARBD (Royal College of Psychiatrists, 2014).

9.2.17 In patients who continue to drink, it can be challenging to properly assess and treat the underlying mental health problem with community mental health services unwilling to assess patients until abstinence has been achieved (Lingford-Hughes et al, 2012). NICE recommend that, in patients' comorbid for alcohol dependence and depression and/or anxiety, the alcohol dependence should be treated in the first instance as this can lead to significant improvement in the mental health symptoms (NICE, 2011).

9.2.18 The difficulty arises, therefore, in dependent drinkers unwilling/unable to consider abstinence who present with lowered mood particularly when associated with suicidal ideation/behaviour. These patients tend to present frequently to crisis services and the cognitive impairment of ARBD will further impact on their ability to engage with treatment services.

9.2.19 Even in patients who continue to drink, if there is a presentation of moderate-severe depression, it is prudent to complete at least some degree of assessment which, at the very least, would comprise an immediate risk assessment. It is important that crisis mental health services do not include acute intoxication as an exclusion criteria particularly when judged on a threshold breath-alcohol limit as, due to the development of tolerance to the sedating effects of alcohol, individuals with high breath-alcohol levels can still engage in meaningful conversations. The level of cognitive impairment also needs to be borne in mind as does potential use of the MHA where appropriate.

9.2.20 Psychosis in relation to alcohol dependence tends to be a manifestation of complicated withdrawal (e.g. the visual and tactile hallucinations seen in delirium tremens). However, there is a recognised psychotic disorder, not explained by intoxication nor withdrawal alone, characterised by hallucinations (typically auditory), perceptual distortions, delusions (often of a persecutory nature), psychomotor disturbances and an abnormal affect (World Health Organisation, 1992). Some individuals with ARBD with complex confabulation may present as if suffering from delusional beliefs. A full mental health and cognitive assessment, including collaborative history and consideration of the past history, is vital in distinguishing between these two presentations.

Further progression

9.2.21 Continued drinking in patients with ARBD is likely to lead to further cognitive decline and the patient and their carers should be made aware of this. Even if treatment has been turned down in the past, it should not exclude them from accessing care in the future. Patients should be encouraged to return to treatment services for reassessment if they are concerned about their cognitive function. Carers (both professional and family/friend) need also to be aware of the potential for loss of capacity to make decisions and the appropriate legal protection that would then need to be put in place. See: What is alcohol-related brain damage? | Alcohol Change UK

9.3 Recommendations

9.3.1 Health Boards in conjunction with Substance Misuse Area Planning Boards in Wales should commission specialist Alcohol Liaison Assertive Outreach Teams, for patients at risk of, or diagnosed with ARBD.

9.3.2 Social care, housing and allied services ensure comprehensive accommodation and care provision, tailored to assessed need and not requiring abstinence from alcohol as a prerequisite.

10. Monitoring, surveillance, evaluation and UK-wide collaboration

10.1 Background

10.1.1 Monitoring the prevalence of ARBD in the UK has been highlighted as a key challenge facing health and social care systems due to the absence of a clear system for capturing, sharing and aggregating case data (Boughy, 2007; Wilson et al., 2012). This was apparent in a recent study that aimed to provide an estimate of alcohol-related neurocognitive disorders prevalence in South Wales through a survey of clinical, social, community, and housing services, using a broad definition that included those with WKS, ARD, and ARBD. While an age-specific prevalence of 34 per 100,000 was reported this is likely to be a conservative estimate due to inconsistencies in diagnosis, monitoring and surveillance (Heirene et al., 2020).

10.1.2 In Wales, a recent investigation found that health and social care professionals reported a poor level of inter-service communication regarding individuals with ARBD and that support services typically obtained case information from referral reports that provided little information about the person's condition or the origin of their diagnosis (Heirene, 2019; Heirene et al., 2021).

10.1.3 This and previous evidence (e.g., Boughy, 2007) also highlighted a general lack of consensus between services as to who should assume responsibility for those with the condition, with patients frequently being "passed from pillar to post" (Heirene et al., 2019).

10.2 Evidence

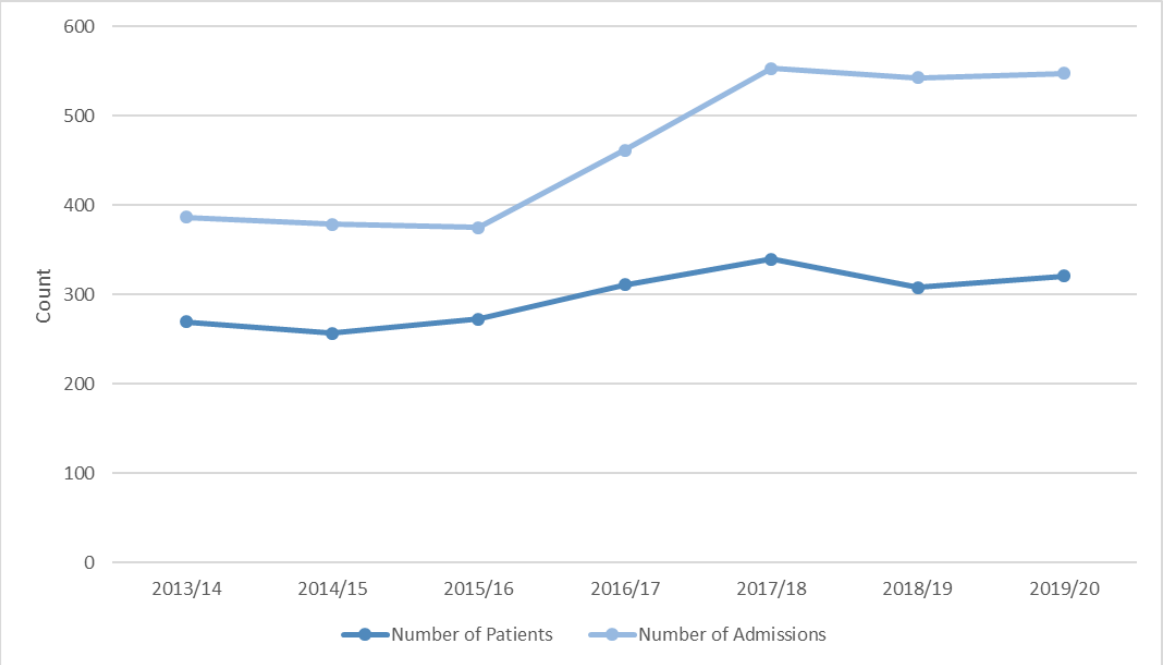
Monitoring and surveillance

10.2.1 Monitoring of ARBD cases in Wales is currently achieved through recording hospital admissions using ARBD-related International Classification of Diseases-10/ 111 (ICD; World Health Organisation, 1992/ 2018) codes and through Specialist Substance Misuse Service patient management data systems. The latter, however, while useful for documenting and sharing detailed patient information, does not provide a suitable avenue through which ARBD case data can easily be aggregated to inform the understanding of the incidence and prevalence of the condition.

10.2.2 Hospital admissions data are more suited to establishing prevalence and incidence and has been utilised to summarise ARBD-related hospital

attendance in Wales between 2008 and 2012 (Emmerson and Smith, 2010). Figure 2 below displays updated admissions for ARBD in Wales from 2013-14 to 2019-20.

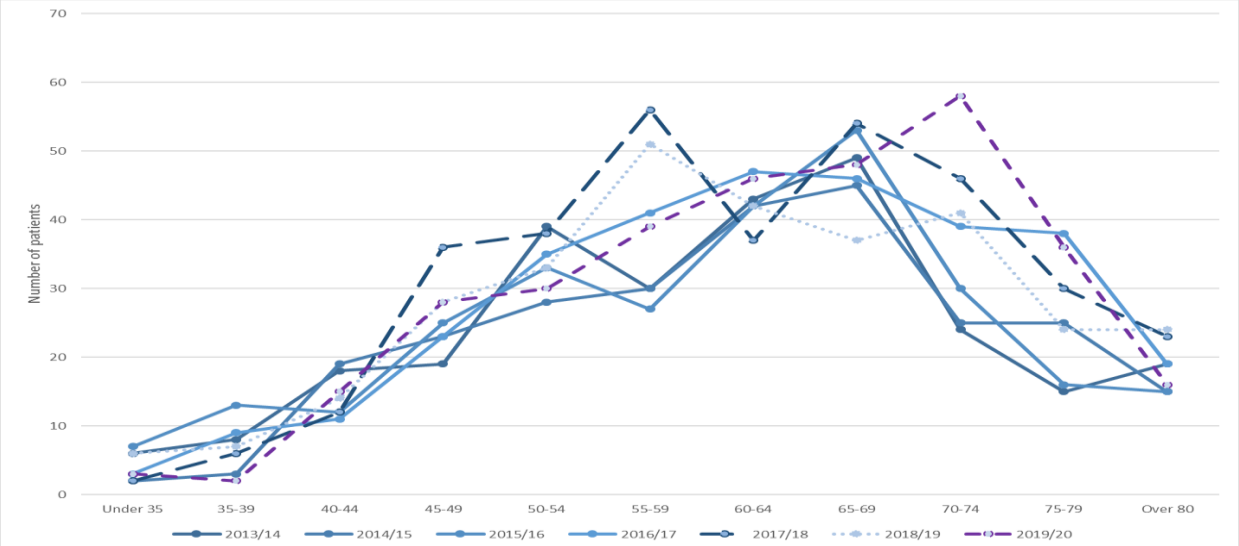
10.2.3 Over the seven year period there has been an 18.9% increase in the number of patients diagnosed with ARBD with a corresponding 41.6% increase in hospital admissions, from 387 admissions in 2013-14 to 548 in 2019-20. It is not possible to establish the degree to which increased awareness and improvements in diagnosis over this time may account for the increase. In 2019-20, the ratio of male to female patients is approximately 2:1.



Source: Patient Episode Database Wales, National Welsh Informatics Service (2020)

Figure 2: Hospital admissions and unique patients admitted with diagnosis of ARBD in Wales 2013-14 to 2019-20.

10.2.4 The age profile of patients diagnosed with ARBD (broad definition) is shown in Figure 3. In 2019-20, there were a total of 321 individuals hospitalised with a diagnosis of ARBD. The age group with the highest number of diagnoses was 70-74 years, followed by those in the 60-69 age categories. Over the last seven years since 2013-14, 17.3% of ARBD diagnoses occurred in those aged under 50 years.

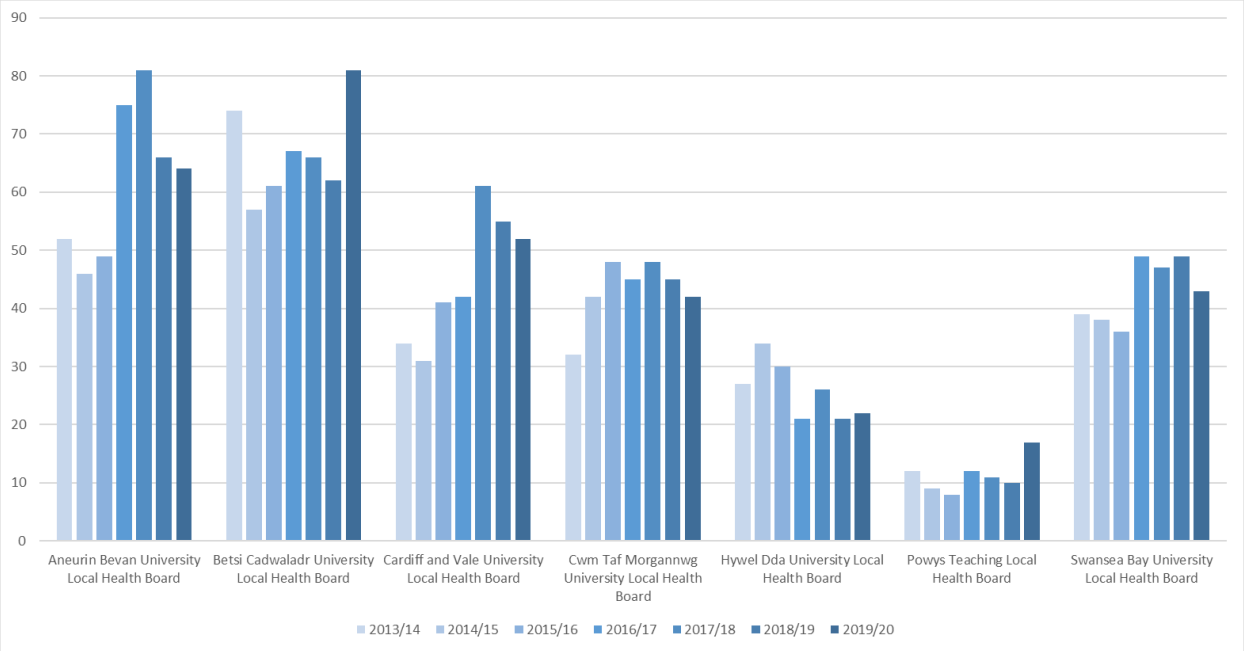


	2013/14	2014/15	2015/16	2016/17	2017/18	2018/19	2019/20
Under 35	6	2	7	3	2	6	3
35-39	8	3	13	9	6	7	2
40-44	18	19	12	11	12	14	15
45-49	19	23	25	23	36	28	28
50-54	39	28	33	35	38	33	30
55-59	30	30	27	41	56	51	39
60-64	43	42	42	47	37	42	46
65-69	49	45	53	46	54	37	48
70-74	24	25	30	39	46	41	58
75-79	15	25	16	38	30	24	36
Over 80	19	15	15	19	23	24	16
Total	270	257	273	311	340	307	321

Source: Patient Episode Database Wales, National Welsh Informatics Service (2020)

Figure 3: Unique patients admitted with diagnosis of ARBD in Wales 2013-14 to 2019-20.

10.2.5 The number of patients diagnosed with ARBD by Health Board area of residence over the seven year period 2013-14 to 2019-20 is shown in Figure 4. The highest numbers of patients admitted for ARBD are recorded in Aneurin Bevan and Betsi Cadwaladr University Health Boards.

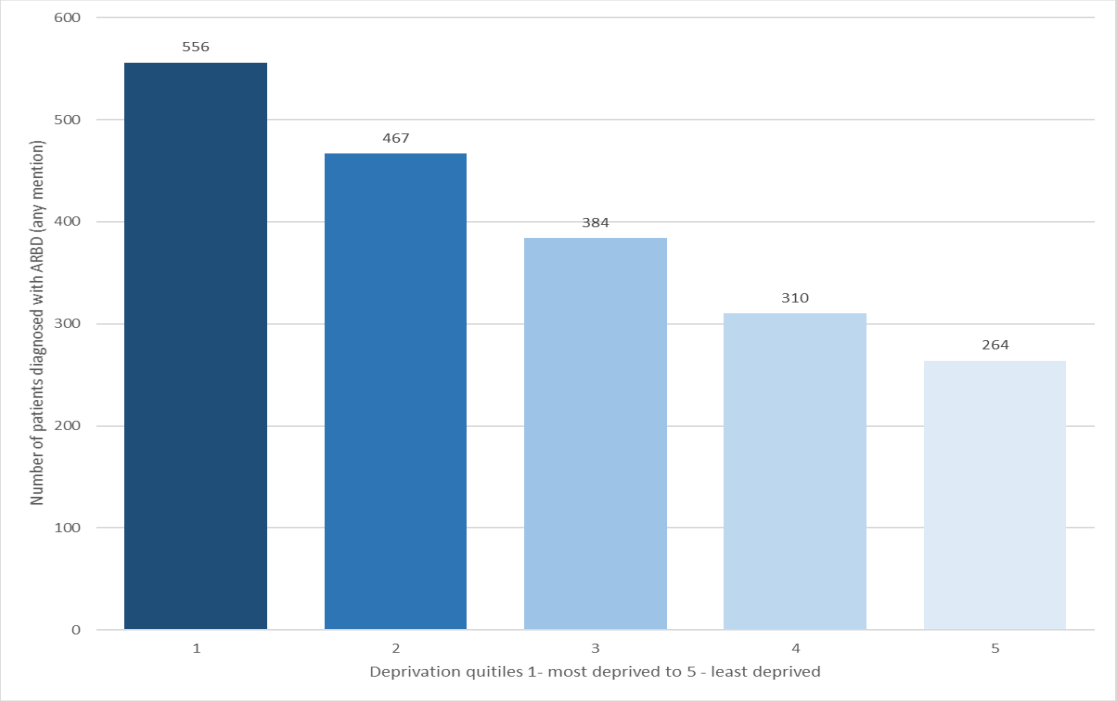


Source: Patient Episode Database Wales, National Welsh Informatics Service (2019).

Figure 4: Unique patients admitted with diagnosis of ARBD by Health Board area of residence in Wales 2013-14 to 2019-20.

10.2.6 There is considerable evidence of a relationship between substance misuse including problematic alcohol use and deprivation. The Welsh Government produces an index of multiple deprivation which ranks every lower super output area (LSOA, small geographical areas with stable populations of about 1,500) on measures of deprivation. These measures allow every address in Wales to be allocated to a quintile of deprivation and ranked from 20% most to 20% least deprived. Hospital admission data includes details of these quintiles[9]. Figure 5 shows the number of all patients resident in Wales with an ARBD diagnosis and admitted to hospital by each deprivation quintile. As indicated, there is evidence of a relationship, with twice the number of ARBD patients resident in the highest deprivation quintile compared with the number of those resident in the least deprived quintile.

[9] Note that deprivation is a measure of the area in which an individual lives, rather than an evaluation of their particular circumstances.



Source: Patient Episode Database Wales and Welsh Index of Multiple Deprivation, National Welsh Informatics Service (2020)

Figure 5: Number of all individuals resident in Wales admitted to hospital and receiving ARBD diagnosis in any position by deprivation quintile in Wales 2013-14 to 2019-20.

10.2.7 Although easily aggregated, there are considerable limitations to the use of hospital admissions data for ARBD monitoring. Anecdotal reports from Welsh clinicians suggest that the ICD codes used to label ARBD-related admissions are rarely applied, particularly when ARBD is not the primary reason for admission (Heirene et al., 2018). These reports are corroborated by Wilson and colleagues (2012), who noted that individuals with ARBD are unlikely to be officially diagnosed or have their condition reported in acute hospital records.

10.2.8 In addition, it has been suggested that hospital staff may be poor at detecting ARBD due to the absence of validated risk assessment tools (Thomson et al., 2012). Thus, the true number of hospital admissions of those with ARBD is likely to be considerably greater than hospital data would suggest.

10.2.9 The issue is further compounded by the confusion surrounding ARBD diagnoses (Emmerson & Smith, 2015) and the lack of a specific “ARBD” diagnosis within the ICD, leaving clinicians to choose between the codes for alcohol-amnestic disorder/KS or alcohol-related dementia, despite the recent impetus for a move towards using ARBD as a diagnostic term in UK clinical practice (e.g., Wilson et al., 2012).

10.2.10 More comprehensive monitoring systems will likely require the consolidation of hospital and community-based records from a variety of settings. The multifarious and complex needs of this population can mean they first present to a variety of different services, including community mental health teams, prisons, social services, GP surgeries, community-based recovery organisations and homeless hostels (Royal College of Psychiatrists, 2014).

10.2.11 Close monitoring of homeless populations may be particularly important given the high prevalence of substance misuse and ARBD within this population. Gilchrist and Morrison (2005) found 21% of 266 homeless individuals in Glasgow met the criteria for ARBD (compared with estimated whole population prevalence rates of 0-2.8% for WKS; Ridley & Draper, 2015), demonstrating the disproportional risk in this population.

Evaluation of specialist service provision

10.2.12 Systematic evaluations of ARBD services in Wales are absent, likely due to the limited number of such services and the relative infancy of those in existence. Nonetheless, in South Wales, service evaluations of Gwent Specialist Substance Misuses Service's ARBD Clinic and Brynawel Rehabilitation Service have been undertaken.

Brynawel Rehab

10.2.13 Brynawel Rehab is a provider of residential treatment for drug and alcohol dependencies, located in Rhondda Cynon Taf (RCT). In 2014 a task and finish group was established after social workers in the RCT area had identified a need for local services for patients with ARBD. From this, in 2015, a pilot study of residential cognitive rehabilitation was established at Brynawel, based on six patients over a six month period. Quantitative and qualitative data was recorded for the six pilot patients and, although the sample size was small, a number of positive findings were demonstrated, including modest improvement in cognitive functioning, noticeable changes in social abilities and improved quality of life. The evaluation period of six months is shorter than the three year potential window for improvement noted by Wilson et al 2015). The cognitive rehabilitation programme is now an established part of the treatment options available at Brynawel Rehab.

Gwent Specialist Substance Misuse Service (GSSMS) ARBD Clinic

10.2.14 GSSMS is the statutory provider of complex needs drug and alcohol treatment in the Aneurin Bevan University Health Board area. In 2014 established a dedicated medical clinic for assessment and diagnosis of ARBD and, with time, further support and management options were developed. The clinic currently provides:

- Assessment and diagnosis (including full physical and mental health assessments).
- Ward liaison assessments and advice (to both mental health and physical health wards).
- Inpatient alcohol detoxification.
- Follow-up to monitor changes in cognitive function.
- Psychosocial interventions modified to take account of cognitive impairment (a specific workbook was developed).
- Low key cognitive rehabilitation (utilising the Brain Injury Workbook).
- Advice to carers (on use of cognitive aids, legal matters etc).
- Ability to work within legislation (Mental Capacity Act, 2005 and the Mental Health Act 1983) where necessary.

An evaluation of the service was performed in 2017. At the time of the evaluation, 62 patients had been referred to the clinic and there was sufficient data on 22 cases to assess changes to cognitive function, alcohol consumption and hospital readmission rates. Over the time of their involvement with the clinic, the sample showed significant increases in cognitive function (as measured using the ACE-III) and significant decreases in alcohol consumption (taking data from Treatment Outcome Profile (TOPS) forms). Hospital readmission rates showed little change over the course of treatment, but it was noted that the cohort were not frequent attenders initially.

The clinic was established without additional funding and so is limited in its ability to expand. However, even with this minimal investment of resources, significant improvements have been seen.

10.2.15 In North Wales, a general exploration of ARBD has been conducted based on data captured from those with the condition in Carenza Care, a service specifically for those with the condition (Boughy, 2007) but which has since closed. The report includes qualitative outcomes from those with ARBD and their families describing the positive aspects of the service and about the condition in general, but provides little direct evaluation of the interventions received in terms of improved outcomes. The Arbennig Unit, Potens is a registered Residential assessment and rehabilitation unit, providing accommodation and support for 21 people with Korsakoffs Syndrome (ARBD). No systematic evaluation of these services has been undertaken.

10.2.16 Outside of Wales, a number of other naturalistic investigations have explored the efficacy of services – both ARBD specific and non-specific – for supporting and treating those with ARBD:

- Irvine and Mawhinney (2008) investigated the effects of a supported housing project in Northern Ireland for four persons with ARBD, finding variable levels of improvement in mental and physical health and

engagement with family; while the ability to complete activities of daily living decreased or remained the same.

- Wilson et al. (2012) have also published a summary of the outcomes from their community-based psycho-social rehabilitation programme for ARBD in Liverpool, again reporting improvements in several outcomes – most notably an 85% reduction in hospital bed use.

- More broadly, the Mental Welfare Commission for Scotland (MWCS; 2010) met with several individuals with ARBD (and the staff surrounding them) in hospitals, care homes and community settings to explore the efficacy of the care they were receiving. The report of findings highlighted positive improvements in some of the group's symptoms as a result of the interventions they had received; though also highlighted a number of concerns including: the lack of appropriate therapeutic and leisure activities for this group in services, the absence of treatment goals in many cases, and the dearth of specialised training available for staff (MWCS, 2010).

UK-wide collaboration

10.2.17 UK-wide collaboration regarding ARBD is currently scant, leaving open the opportunity for significant development in this area. Greater collaboration across the UK is required to improve identification, diagnosis, treatment and care. Indeed, Thomson and colleagues argued in 2012 that a single risk assessment tool and clear treatment guidelines should be adopted in the UK; though this suggestion is yet to be implemented.

10.3 Recommendations

10.3.1 Support a comprehensive and co-ordinated programme of evaluation including validation of ARBD screening and diagnostic tools, rehabilitative models of care, integrated care pathways and community support services.

10.3.2 Support robust surveillance and clinical research studies to evidence the nature and scale of ARBD and at risk populations within Wales, identify pharmacological and dietary protective/risk measures and interventions and inform further planning and commissioning of integrated care.

11. Welsh Language

11.1 Given the cognitive issues associated with ARBD, to ensure that individuals can fully engage with a service and benefit from the overall outcome of the intervention, where an individual speaks Welsh, there should be a commitment and active engagement to provide services in Welsh where possible.

11.2 Services should ensure that access to services in Wales are provided in Welsh and English in accordance with the Welsh Language (Wales) Measure 2011, any relevant Welsh language standards and the *More than just words* framework.

11.3 In practice, this will include the following:

i. Ensure that any written material produced, including digital material, is bilingual.
ii. Ensure that any signage is bilingual.
iii. Ensure that any training or public events are held bilingually.
iv. Actively promote and facilitate the Welsh language (including providing services and increasing opportunities to use the Welsh language).

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Appendices

Appendix A - ARBD diagnostic criteria

Introduction:

The diagnostic criteria for Wernicke's Korsakoff's Syndrome (WKS), Alcohol-Related Dementia and ARBD are presented below. While the distinctions between WKS, ARD and ARBD diagnoses have been debated due to their overlapping symptomology and the heterogeneity within these groups (Zhar et al., 2011; Bowden, 1990), the diagnostic distinction still offers some merit for clinicians in understanding how classic Wernicke's and Korsakoff's Syndrome presentations might differ from the criteria proposed for ARD and ARBD. It is important to note, however, that the criteria for ARBD proposed by Wilson (2013) are yet to be empirically validated. Nonetheless, they provide a pragmatic and inclusive approach to diagnosing alcohol-related neurocognitive impairment that appears well-used in current clinical practice.

Wernicke-Korsakoff Syndrome: International Classification of Diseases-11 (2018) – (Code: 5B5A.1)

"Description: A thiamine-deficiency syndrome characterized by symmetric hyperaemic lesions of the brainstem, hypothalamus, thalamus, and mammillary bodies with glial proliferation, capillary dilatation, and perivascular haemorrhage. The syndrome is manifested by a confusional state, disorientation, ophthalmoplegia, nystagmus, diplopia, and ataxia (Wernicke encephalopathy), with severe loss of memory for recent events and confabulation (the invention of accounts of events to cover the loss of memory) (Korsakov psychosis) occurring following recovery. Defective binding of thiamine diphosphate by transketolase has been found. It appears that the disorder is of autosomal recessive inheritance but is expressed as clinical disease only in the event of thiamine deficiency."

Reference: World Health Organisation (2018). International Classification of Diseases-11 for Mortality and Morbidity Statistics (online draft). Retrieved from: ICD-11 - ICD-11 for Mortality and Morbidity Statistics (who.int)

Dementia due to use of alcohol: International Classification of Diseases-11 (2018) – (Code: 6D84.0)

"Description: Dementia due to use of alcohol is characterized by the development of persistent cognitive impairments (e.g., memory problems, language impairment, and an inability to perform complex motor tasks) that meet the definitional requirements of Dementia that are judged to be a direct consequence of alcohol use and that persist beyond the usual duration of alcohol intoxication or acute withdrawal. The intensity and duration of alcohol use must have been sufficient to produce the cognitive impairment.

The cognitive impairment is not better accounted for by a disorder or disease that is not induced by alcohol such as a dementia due to another disorder or disease classified elsewhere."

Reference: World Health Organisation (2018). International Classification of Diseases-11 for Mortality and Morbidity Statistics (online draft). Retrieved from: ICD-11 - ICD-11 for Mortality and Morbidity Statistics (who.int)

Alcohol-Related Brain Damage: Wilson (2013)

"A. Criteria for the clinical diagnosis of probable ARBD include the following:

Evidence of cognitive impairment (as demonstrated by clinical examination or use of appropriate instruments)

Significant history of alcohol use as defined by the minimum average of 35 standard drinks per week for men and 28 for women for a period of greater than 5 years. The period of significant alcohol use must occur within three years of the onset of cognitive deficits.

B. The diagnosis of ARBD is supported by the presence of the following:

Alcohol-related hepatic, pancreatic, gastrointestinal, cardiovascular or renal disease or other end organ damage

Ataxia or peripheral polyneuropathy (not attributable to other non-alcohol related causes)

Neuroimaging evidence of cerebellar atrophy, especially of the vermis

Cognitive damage and evidenced ventricular or sulcal dilatation are likely to improve within the first 60 days, residual damage will be slower to improve.

C. The following clinical presentation indicates that there may be complicating conditions such as vascular or traumatic lesions:

The presence of language impairment, especially dysnomia or anomia
The presence of focal neurological signs or symptoms (except ataxia or peripheral sensory polyneuropathy)

Neuroimaging evidence of cortical or subcortical infarction, subdural haematoma or other focal brain pathology

Elevated Hachinski Ischemia scale score"

Reference**:** Wilson, K. (2013). Alcohol-related brain damage in the 21st century.

Alcohol-induced major neurocognitive disorder (amnestic and non-amnestic types): Diagnostic Statistical Manual-5 (2013)

"Diagnostic criteria for 'substance/ medication-induced mild or major neurocognitive disorder':

> A) The criteria are met for major or mild neurocognitive disorder (NCD; see next page for criteria)
>
> B) The neurocognitive impairments do not occur exclusively during the course of a delirium and persist beyond the usual duration of intoxication and acute withdrawal.
>
> C) The involved substances or medication and duration and extent of use are capable of producing the neurocognitive impairment
>
> D) The temporal course of the neurocognitive deficits is consistent with the timing of substance or medication use and abstinence (e.g., the deficits remain stable or improve after a period of abstinence).

Diagnostic features relating to alcohol-induced Neurocognitive disorder (NCD):

Substance/ medication-induced major or mild NCD is characterized by neurocognitive impairments that persist beyond the usual duration of intoxication and acute withdrawal (Criterion B). Initially, these manifestations can reflect slow recovery of brain functions from a period of prolonged substance use, and improvements in neurocognitive as well as brain imaging indicators may be seen over many months. If the disorder continues for an extended period, persistent should be specified.

NCD induced by alcohol frequently manifests with a combination of impairments in executive-function and memory and learning domains. The temporal cause of the substance-induced NCD must be consistent with that of the use of a given substance (Criterion D). In alcohol-induced amnestic confabulatory (Korsakoff's) NCD, the features include prominent amnesia (severe difficulty learning new information with rapid forgetting) and a tendency to confabulate. These manifestations may co-occur with signs of thiamine encephalopathy (Wernicke's encephalopathy) with associated features such as nystagmus and ataxia. Ophthalmoplegia of Wernicke's encephalopathy is typically characterized by a lateral gaze paralysis."

Reference: American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders (5th ed.). Arlington, VA: American Psychiatric Publishing.

Appendix B – Provision of Pabrinex® - British National Formulary

VITAMIN B SUBSTANCES WITH ASCORBIC ACID | Drug | BNF content published by NICE

Treatment of suspected or established Wernicke's encephalopathy, by intravenous infusion of I/V High Potency, 2–3 pairs 3 times daily for 3-5 days; followed by 1 pair once daily for a further 3-5 days or for as long as improvement continues."

"Prophylaxis of Wernicke's encephalopathy (assisted alcohol withdrawal in an inpatient setting) by deep intramuscular injection into the gluteal muscle, 1 pair once daily for at least 5 days and up to 7 days if required."

"Dose is expressed in pairs of ampoules.

For intravenous administration, 1 pair is one 5 mL ampoule containing thiamine 250 mg, riboflavin 4 mg and pyridoxine 50 mg, and one 5 mL ampoule containing ascorbic acid 500 mg, nicotinamide 160 mg and glucose 1000 mg.

For intramuscular administration, 1 pair is one 5 mL ampoule containing thiamine 250 mg, riboflavin 4 mg and pyridoxine 50 mg, and one 2 mL ampoule containing ascorbic acid 500 mg and nicotinamide 160 mg."

Ampoule 1 of 5ml Pabrinex® contains 250mg thiamine hydrochloride. BNF guidelines for the treatment of Wernicke's encephalopathy is two to three pairs of IV Pabrinex® each day for two days (2,000mg to 3,000mg thiamine hydrochloride per day). For prophylaxis it is one pair IM Pabrinex® each day for five days (500mg thiamine hydrochloride per day). Pabrinex® is comprised of two ampules. Ampoule one contains thiamine hydrochloride, riboflavin and pyridoxine hydrochloride and will not be administered. Ampoule two contains ascorbic acid, nicotinamide and anhydrous glucose.

Appendix C – Neuropsychological assessments

Table 5. Cognitive screening instruments (CSIs) for ARBD assessment

Test	Description	Functions assessed	Strengths	Limitations	Sensitivity and specificity at optimal cut-off scores
ACE-III	Designed for the detecting of mild-cognitive impairment and dementia. Individual sub-test scores can be calculated as well as a total score. The typical cut-off for dementia is 88 or 82 (of 100). Administration time: 15-20 minutes.	Attention Memory Fluency Language Visuospatial processing	Provides a more comprehensive assessment of cognition than the MoCA & MMSE. Validated for use with individuals diagnosed with ARBD & KS. Online training easily accessible: https://www.mvls.gla.ac.uk/aceIIItrainer/	Limited assessment of executive functions. Longer administration time than the other CSIs presented here.	Brown et al. (2018): ARBD vs. ALs, cut off: ≤86 (sensitivity = 82%; specificity = 73%).
BEARNI	Designed as an easily administered CSI for assessing the key cognitive &	Memory Visuospatial abilities Fluency Ataxia	Provides an assessment of the key areas of cognition expected to be impaired in ARBD & an assessment of	Limited assessment of executive functions. Yet to be validated for use with populations	Ritz et al. (2015): ALs vs. healthy controls: sensitivity = 98.4%; specificity = 50%.

Test	Description	Functions assessed	Strengths	Limitations	Sensitivity and specificity at optimal cut-off scores
	motor deficits associated with alcoholism. Administration time: 15-20 minutes.		ataxia – a frequent motor impairment.	meeting ARBD criteria.	
MMSE	Brief CSI designed for dementia screening. Provides sub-test and overall scores with a maximum of 30 and standard cut-off point of <24. Administration time: 5-10 minutes.	Orientation Attention Calculation Language Memory Comprehension Copying	High sensitivity and specificity values have been found, albeit lower than those for the MoCA. The test is easily administered and assesses multiple functions.	No assessment of executive abilities. Poor assessment of memory that has been found to be insensitive to memory problems; even the severe amnesia of KS.	Oudman et al. (2014): KS vs. healthy controls, cut off: ≤26/ 27 (sensitivity = 90/100%; specificity = 83.3/ 73.3%).
MoCA	Designed for the detection of mild cognitive impairment and dementia. Provides	Memory Fluency Attention & concentration Language Visuospatial abilities Orientation	High sensitivity and specificity values have been identified for the MoCA when using adjusted cut-off scores (see across),	Limited assessment of executive functions.	Oudman et al. (2014): KS vs. healthy controls, cut off: ≤22/23 (sensitivity = 100/ 100%; specificity = 100/ 96.7%).

Test	Description	Functions assessed	Strengths	Limitations	Sensitivity and specificity at optimal cut-off scores
	sub-test and overall scores with a maximum of 30 and standard cut-off of <26. Administration time: 10 minutes.		indicating that those with ARBD will typically score below the cut-off score & those without will score above. The test is easily administered & assesses most basic functions.		Wester, Westhoff et al. (2013): KS vs. mildly impaired alcoholics, cut off: ≤20 (sensitivity = 73%; specificity = 75%).
TEDCA	Designed as an easily administered CSI specifically for assessing the key cognitive deficits associated with alcoholism. Administration time: 8-10 minutes.	Memory Visuospatial abilities Executive functions	Provides an assessment of the key areas of cognition expected to be impaired in ARBD. Extensive assessment of executive function.	Yet to be validated for use with populations meeting ARBD criteria.	Jurado-Barba et al. (2017): ALs vs. healthy controls: sensitivity = 67%; specificity = 76.7%.

Tests: ACE-III = Addenbrooke's Cognitive Examination-3; BEARNI = Brief Examination of Alcohol-Related Neuropsychological Impairments; MMSE = Mini-Mental Status Examination; MoCA = Montreal Cognitive Assessment; TEDCA = Test of Detection of Cognitive Impairment in Alcoholism.

Samples: ALs = alcohol-dependent persons with no diagnosed cognitive impairment; ARBD = alcohol-related brain damage; KS = Korsakoff's Syndrome.

Table 6 displays the average ACE-III performance by alcoholic-dependent individuals with and without ARBD as the ACE is the most commonly used test in South Wales to assess ARBD (Heirene et al., 2019)

	Index (maximum score)	Mean (SD)	
		Alcoholics without ARBD	ARBD
ACE-III	Total score (100)	89.4 (8.9)	78.5 (10.3)
	Attention (18)	17.1 (1.2)	15 (3)
	Memory (26)	21.3 (4)	16.2 (4.6)
	Fluency (14)	12 (2.3)	9.8 (2.6)
	Language (26)	24.3 (2.9)	23.5 (1.6)
	Visuospatial (16)	14.7 (1.3)	14.1 (1.8)

Table 6. ACE-III performance by alcoholic-dependent individuals with and without ARBD

Note: these test scores should be used as a guide only as the cognitive profile of those with ARBD frequently varies and can be influenced by a variety of factors (e.g., age, comorbid disorders, recent intoxication etc.)

Table 6. ACE-III performance by alcoholic-dependent individuals with and without ARBD

Domains of neuropsychological assessment (further details)

Memory is one of the most impaired cognitive domains in ARBD (see Appendix XX), warranting further assessment following initial screening to better characterise the memory disorder. The most useful tests of memory identified by Heirene et al. (2018a) were the Rivermead Behavioral Memory Test (RBMT; Wilson et al., 1989) and the California Verbal Learning Test (CVLT; Delis et al., 1987). The RBMT was designed as an ecologically focused memory test, offering clinically and practically useful information about a person's memory deficit. The CLVT is a more detailed verbal memory assessment that provides a wealth of information regarding memory function that could inform treatment approaches.

Executive dysfunction has also been reported in those with ARBD, with specific executive skills differentially affected (Maharasingam, Macniven, & Mason, 2013). Based on the available evidence, Heirene et al. (2018a) recommended the Behavioural Assessment of the Dysexecutive Syndrome (BADS; Wilson, Alderman, Burgess,

Emslie, & Evans, 1996) as the most useful test for assessing executive function in ARBD. The BADS assesses multiple executive skills in an ecologically focused format and has demonstrated a high level of sensitivity to the cognitive impairments associated with ARBD (Maharasingam et al., 2013; van Oort & Kessels, 2009).

Heirene and colleagues (2018a) observed that those with ARBD also display deficits on subtests of **intelligence batteries** – namely those involving the assessment of processing speed, executive functions and working memory. The intelligence test with the largest evidence base to underpin its use in ARBD assessment is the Wechsler Adult Intelligence Scale (WAIS; Wechsler, 1958), which is often viewed as the gold-standard assessment of intelligence (Hayes et al., 2016). Since Heirene and colleagues' review, a second battery test has also been evaluated for ARBD assessment and diagnosis: the Repeatable Battery for the Assessment of Neuropsychological Status (R-BANS). Brown et al. (2019) found an optimum cut-off score of ≤83 produced a sensitivity of 89% and specificity of 67% for the R-BANS when comparing those with ARBD (including KS) and alcoholics without ARBD. The diagnostic capabilities of the R-BANS were superior to those of the ACE-III in these populations, although not significantly so.

The final area of neuropsychological assessment concerns the evaluation of **pre-morbid ability**. That is, an assessment (or estimate) of a person's cognitive ability prior to the onset of ARBD, thereby allowing clinicians to more accurately determine the extent of their impairment. The most commonly used and well-validated method for this purpose is the National Adult Reading Test-Revised (NART-R; Bright, Hale, Gooch, Myhill, & van der Linde, 2016), which assesses a person's ability to recognise and pronounce phonetically irregular word. The test is predicated on the assumption that vocabulary is highly correlated with intelligence and relatively impervious to most forms of brain damage.